

MENTAL RETARDATION LECTURES

SHELTERING ARMS TRAINING PROGRAM

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We regret that it was not possible for us to include Dr. Paul Elwood's lecture on "Medical Aspects of Mental Retardation.

INTRODUCTION

The rapid expansion of the field of mental retardation over the past several years has highlighted the acute need for more trained workers at both professional and non-professional levels. The training program conducted by The Sheltering Arms School in Minneapolis, under a contract with the Mental Retardation Branch of the United States Public Health Service, represented a community-wide attempt to explore training techniques and to attract people to work in this area.

The training program served a total of thirty-nine trainees in three groups; the training period was eight weeks in length for each group. Trainees represented a wide range of educational background and experience in the field. Some were high school graduates, with no previous exposure to mental retardation; others had master's degrees and years of experience as teachers and social workers. One was a psychologist with a Ph. D. degree. The geographical range was also wide. Trainees came to the program from Minnesota, South Dakota, Nebraska, Illinois, Indiana, Massachusetts, Pennsylvania, Arkansas, and Texas. Inquiries about the program came from many other states, from Canada, and from India.

The content of the training program consisted of three aspects: in-service placements in a variety of community programs and agencies; a lecture series covering basic factual material about mental retardation and services in this field; and selected readings which trainees carried on outside the working day hours. Trainees were evaluated by their supervisors in the in-service placements, and also took a final examination covering the content of the lecture series. Trainees, in turn, were asked to evaluate the training program at the close of the eight week period.

The Sheltering Arms staff carried major responsibility for planning and carrying out the program, but this would not have been possible without two essential sources of help. We are grateful to the United States Public Health Service for the financial support which made the program possible, and in addition, we wish to express our deepest appreciation to the many community programs and agencies which so generously opened their doors to the trainees on in-service placements, without whose help the program could not have been undertaken at all. A special word of thanks is due our faithful lecturers who contributed their knowledge and experience through the lecture series.

The suggestion of compiling the lectures into published form came from the trainees. We hope this volume will be of interest and value not only to the trainees however, but to other people concerned with the multiple problems of mental retardation.

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A FACTUAL REVIEW OF MENTAL RETARDATION

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As we begin the lecture series of this training program, it seems appropriate to do some reviewing of the basic concepts concerning mental retardation. Although various definitions of mental retardation have been formulated, the essential component is sub-average intellectual capacity. In children, this is basically defined by inability to learn normally; in adults, by inability to be self-sustaining and independent in terms of expectations set by society for adults. Mental retardation is a multiple problem. Its dimensions are bounded only in part by degree of intellectual defect, although this is an important boundary. They are also formed by: patterning of Intellectual abilities, which may affect learning progress and adaptation to work; patterning of emotional reactions, which in turn may be affected by organic - causation factors as well as by experience and native endowment; patterns of behavioral adjustment, which in turn are determined both by causation factors and by life experience; aspects of physical health and added sensory or motor handicaps; patterns of family climate, important in all aspects of child growth and development; and by patterns of societal attitude and provision for retardates, which affect opportunity for education, recreation, employment, and which broadly shape the environmental climate for retarded individuals.

Mental retardation includes a wide range of disability. Groupings of degrees of retardation were made long before psychological tests permitted more exact numerical expression. Historically, three broad groups of retardates were defined - the idiot, the imbecile, and the moron groups. The development of psychological tests led to the use of IQ groupings as "short cut" descriptions of functioning ability levels. Studies of mental growth processes and the development of intelligence contributed further to our understanding of mental retardation and to our ability to predict final levels from childhood measures of ability.

Intelligence develops on a time schedule, with both maturation and learning involved. The organism arrives in the world with genetic, biological potential for growth and development of all capacities. This potential varies from one person to another, presumably on a genetic basis, and giving rise to the whole concept of individual differences. Some retardates apparently do not have specific causes for slower than normal rates of development, other than the genetic inheritance they happened to get through hereditary transmission - they form the "garden variety" group, to use the terra Sarason uses. The further down we go on the scale of intelligence,

the higher the incidence of other associated defects and, in general, the greater the likelihood that medicine and/or genetics can point out specific causative factors.

In infants and young children, the early manifestations of intelligence are seen in ability to pay attention, to notice, in locomotor and motor development, in ability to make simple discriminations, in ability to acquire information. The comprehension of language and language development introduces another dimension. With further development time, comes the emergence of abilities to compare and differentiate further and the development of thinking, reasoning, judgment, symbol manipulation, and abstract concept appreciation and use. Although many tests of intelligence have been developed on the basis of specific kinds of ability, most theories of intelligence are based on the concept of a general kind of intellectual ability. Mental growth, like physical growth, proceeds rapidly at early ages and then less rapidly in later childhood, leveling off somewhere in middle adolescence for normal ability ranges, continuing to a somewhat later age for gifted people, and coming to a halt sooner for retarded groups. The more limited the intellectual potential, the earlier the age of completion of the mental growth process.

Tests of intelligence were developed for highly practical purposes - school grouping and educational planning. Binet is credited with developing the first useful intelligence test, and his work furnished the basis for later refinement of testing processes. We should perhaps talk specifically about some of the kinds of measures of intelligence which are in use now.

Group tests of intelligence have been constructed which can be given to a group of children (or adults, for that matter). These are useful as a rough sorting device, for some grouping purposes in school settings, and as a screening technique to locate those children who need individual study. Group tests are generally not very useful with retarded children, and do not furnish adequate information for any individual diagnostic work.

Individual tests are the diagnostic instruments we rely on. They can be further subdivided in terms of scoring systems and kinds of content. Age scales generally make use of standards established for age groups and compare the individual subject with expectations set for the "average" performance. Point scales generally assign points of credit for subtest performances, and the total of points is then translated into a mental age level. Verbal tests are those which make use of language both in presenting test items and in responding to them; performance tests do not require the subject to give verbal replies. Some of them use language directions, but usually can be adapted to administration by pantomime. Tests are standardized by being given to large populations which are selected to be representative of the total population; the individual child

being tested is in effect being compared to the entire standardization group. Many, but not all, tests make use of a mental age concept, which represents the average level of the child's test performances. By comparing the mental age with the child's chronological age, a ratio figure known as the Intelligence Quotient (IQ) is obtained.

In using tests with mentally retarded children, we often do run into a variety of handicaps which make it necessary to make some adaptations of testing procedure. Dr. Holbrook will be talking specifically about some of these problems later in the series; at this point, suffice it to say that when we do deviate from the standardized procedures, we lose some of the accuracy of the testing instrument - but at the same time, we may achieve a better estimate of ability than we could get any other way. The use of psychological tests is a highly technical field. Examiners need rigorous training and considerable supervision while they are learning to use tests meaningfully.

Tests have come in for heavy criticism from many sources. Parents are often suspicious of them - especially parents of handicapped children. They have somehow gotten the cart before the horse and have the idea that it is the test which creates the handicap. Psychological, medical, and educational diagnostic processes with the retarded are not perfect, but the fact remains that these processes, at their present stage of development and perfection, are guides to planning which are far superior to the unsupported subjective judgment of parents, teachers, or other observers of retarded individuals. The most useful single instrument for individual prediction of achievement and adjustment remains the individual intelligence test, administered and interpreted by a well trained and experienced psychologist in the light of the individual's social and developmental history. It is certainly helpful in filling in the picture of the child's total pattern to have available observational and anecdotal data which will bear significantly on total personality and hence on prediction of total adjustment, but these kinds of data must be viewed as supplemental or question-raising rather than final in nature. This is true because of the unstandardized nature of such observations, because of problems of dissimilar frames of reference and comparison, and because of the subjective factors involved in such observations.

Test results are useful in helping us to predict school learning and later goals which will be appropriate for the retardate. Academic goals, especially, can be set at suitable levels for various mental ages and rates of development. For educational planning, knowing the mental age is more helpful than knowing the IQ score, although of course the mental age can be arrived at easily if you have both IQ and age to work from. A six year old with an IQ of 75 is a long way from making progress with reading, whereas a nine year old with an

IQ of 60 is probably considerably closer. Learning achievement is, of course, affected by many other factors than ability level by itself. Ability patterns differ, and some children have specific perceptual defects which interfere markedly with learning progress. Interest and motivation and personality traits can also be quite important. Even so, however, we can make fairly broad predictions which are useful and meaningful on the basis of quantitative and qualitative test performances.

Of course our concern is with more than just school learning. We are concerned also with adult outcomes - vocational possibilities, social adjustment aspects. The evidence of follow-up studies of retarded people is one source of information as to what happens, in adulthood, to people who as children were considered mentally retarded. One such study followed up the same group of retardates at two different times. The first follow up was done during the depression and the second follow up was done in the 1940's. Even during the depression, more than half the subjects were found to be at least partially self supporting, but this number had increased markedly between then and the second follow up, suggesting the importance of the economic climate in relationship to possibilities for self-support. We would expect that changes in social attitudes and acceptance of mental retardation would contribute positively to any such study being undertaken at the present time. Such things as sheltered workshops and vocational rehabilitation programs would be expected to enhance the employability of retardates now.

When we say that the majority of retardates will remain in the community and be at least marginally self-supporting, this is true as far as it goes, but we would further define that portion of the total retardate group for whom it is true. We should also point out how rapidly the numerical incidence of retardation decreases as we move on the curve of normal distribution from the low average to dull-normal to borderline to higher grades of retardation and then down to the trainable and total care levels. Numerically speaking, by far the majority of retardates fall in the educable category. If we look at follow-up data in general, the "marginally self-supporting" statement is true for most of the IQ 65 and up group who are predominantly familial or subcultural in causation type. Many of this group are not in special education programs ever; they are the relatively even-ability patterns who are not in conflict with their families' patterns of achievement or expectation, who move through school as poor achievers but not necessarily as social problems, who get jobs pretty much "on their own" although some of them may be served by special employment help or rehabilitation help. This group does not, typically, include many of the low educables in the general IQ range of 50 to 65, or many of the educables who show organic problems of behavior or emotional adjustment, or many whose family situations have been notably destructive or emotionally non-supportive, or many at the trainable level. Of these latter groups, those who can contribute to their own support are more likely to be those with

fortunate family situations in which limited employment is possible, not those who are dependent on competitive employment for their support.

It begs the question to say that if community attitudes of acceptance and emotional support were different, many of the retarded could be more self-supporting than they are. Abstract attitudes of acceptance and sympathy can, to some extent, be "taught" to a population; concrete attitudes of day-to-day toleration of incompetence in work situations and perhaps even more importantly in social interaction are an entirely different matter, because these attitudes are more tied to individuals' own needs in co-worker situations and hence more tied to self-preservation and self-comfort areas. It is no accident that retarded individuals lose their jobs more often for social reasons than because they are unable to perform the tasks assigned to them. This suggests that our educational programs for the retarded, both educable and trainable, have been, in the past, tied to the wrong objectives. They lose their jobs not because they cannot read but because people cannot put up with their social interaction characteristics. This suggests that we should be developing school curricula for both educables and trainables which are geared to developing acceptable social behavior patterns and work attitudes rather than academic skills, at least for their own sake. In general, the teaching of specific job skills is less useful than the long-term development of good work attitudes. Most of the jobs which truly retarded people will fill are basically unskilled jobs. Their adequate performance is more dependent on responsibility, good habits of being on time, sticking to the task, not getting upset by minor interpersonal difficulties, staying out of trouble with the law and with the neighbors, than on specific job training. This points toward in-service training in the job situation, or in a simulated job situation, rather than long-term specific teaching of complex skills.

The ability of the adult retardate to remain in the community depends upon his social adjustment, his adaptation to job responsibility, and the kind and amount of supervision he requires, as well as on the attitudes of the community. His ability to remain in the community with maximum life satisfaction to himself depends not only on these things but also on the availability of life satisfactions to him. We have tended to argue by analogy that what is good for normal people is, in watered-down form, good for retarded people. There is considerable evidence to the contrary, in the excellent and happy institutional adjustments made by many individuals and attested to not only by observation within the institutional setting but also by parent report on visits at home - even when these parents have initially, and for a long time, opposed institutional placement and have accepted it only when they came to feel that happiness within the home and community was an impossible goal. Retardates themselves have often expressed the feeling of "belonging" in an institutional setting and have shown satisfaction in the companionship of

people like themselves. Many of the community facilities we have been busy trying to develop are, at best, a limited, imperfect form of a good institutional program, which is essentially a "miniature world" in which the retarded individual can adapt and find satisfactions which are lacking to him in the normal world. If we accept the premises that lower-ability retardates (i.e., the majority of trainables, all the sub-trainables, and a considerable proportion of the low educables): 1) cannot "manage their lives with ordinary prudence;" 2) cannot enjoy ordinary social interaction in the normal world; 3) cannot take responsibility for financial aspects of their lives; 4) cannot compete with satisfaction to themselves in any area of normal living; and 5) require considerable protection by family or by family substitutes, then it follows that society as a whole has some available choices between offering the protection, security, cushioning of existence to this group of retardates either through protected community facilities or through institutional facilities. When the argument is advanced that provision of day care facilities reduces the cost to society of caring for the retarded, we should also consider the hidden costs to society inherent in the family sacrifices to protect the retardate and provide for his total needs beyond the "employment hours" of nine to five, which may be met by some community provisions. I believe we cannot afford to neglect the societal contributions of parents who, emotionally and practically, may be tied to the retardate, or the contributions of other family members who may be, to some degree, emotionally and productively crippled by the interlocking, often essentially neurotic relationships which have constituted their "cultural inheritance" within their families. One of the factors in the adjustment of many brain-injured individuals of defective intelligence, both at educable and trainable ability levels, is inability to adapt to change. The institutional setting offers far more possibility of improving total adjustment through lessening the demands for such adaptation than community programs can possibly offer. We should give these factors considerable thought to decision-making.

We have, professionally, in recent years, tended to focus attention on the retardate as an individual to the exclusion of viewing his family as having anything to do but provide for his needs. When we do view him as part of a family unit, it is currently popular to say that this family unit should be protected through the extension of helpful societal resources. I think we often need to do some critical thinking about this viewpoint. We must look not only at the retardate but at the family unit itself. We must develop more skill in diagnosing and dealing with varying degrees of family strength. We must be realistic enough to admit that families differ in strengths - intellectual, emotional, adaptive; that families differ in problems - economic, financial, other life satisfactions available, other demands in terms of number of other children, adjustments, problems, neighborhood assets or detriments, supports or lacks of supports, health problems, marital adjustment problems. For many families, the continued presence of a retarded child who presents difficulties spells

the difference between marginal failure and marginal success, between being an asset or a liability to society. We need to weigh very carefully whether keeping a retarded individual in such a setting justifies the total cost to society of supporting the entire family unit. We talk of supportive services in terms of counseling, therapy, and the like - but I believe we need to recognize that supportive services should be used to support only what is genuinely constructive and useful both to the family and to society as a whole. Many families would not need extensive supportive services if their retarded child were not living in the home. Many times these supportive services cannot provide the needed support anyhow. We need to balance the going against the costs, in terms of numbers, societal contributions, loss of living satisfaction to parents and other family members, as well as in economic terms. I think we still have some things to learn in order to do this "balancing" job wisely and well.

We should perhaps talk a little bit about problems of diagnosis and tools of diagnosis. Thorough medical evaluation is certainly important and unfortunately often not done. There is general agreement that medical training should include more attention to problems of mental retardation. In future lectures you will be hearing about some of the kinds of retardation problems which are now being more completely understood medically and the implications this holds for prevention of some cases of retardation. In studying a child we also need to be sure to include attention to possible sensory defects since these are so important as additional handicaps to learning. Then we need careful evaluations of mental ability. When at all possible, it is valuable to have both a verbal and a performance test, since many retarded children have speech problems and since the two types of tests do tap somewhat different kinds of ability. Among the tests most often used, to which you will be seeing references in your reading, are these: With the youngest age ranges and with more severely retarded children up to later ages, the Cattell Infant Intelligence Scale and the Gesell Developmental Schedules are in common use. The Merrill Palmer Scale is primarily a performance test, useful for normal children up to about age five, but useful with retarded children depending on how severe the retardation is up to age nine or ten and sometimes older. The Stanford Binet Scale is the most commonly used test for children from age two through high school age ranges, and this is the one considered most predictive of school success. The Arthur Performance Scale is another of the performance types of test not requiring verbal replies; it is useful for normal children in the age range of about six to twelve, and for retarded children - again depending on the degree of retardation - from about age nine and up. The Wechsler Intelligence Scale for children is intended for normal children between five and sixteen, but is not very useful for retarded children of educable ability before about age ten. The Wechsler Adult Intelligence Scale can be used for retarded adults, but, again, the more retarded adults would find little on this test with which they could be successful. The Bender-Gestalt is a test

which involves copying drawings and is useful in picking up perceptual-motor defects; it is not an intelligence test as such. The Illinois Test of Psycholinguistic Abilities is a fairly new instrument which has been used more for research purposes than in diagnosis, up to now. There are, of course, other test instruments but these are the ones you are most likely to run across in your readings.

In addition to the medical information, the sensory evaluations, and the intelligence tests, we also need to have background information, descriptions of earlier development, information about the family situation and the emotional climate in which the child has lived. This case history data is usually supplied by parents. It needs to include some facts about health history, birth record, and early development as well as current information. Most textbooks dealing with retardation problems include some kind of case history outline to be used as a guide. We want to know, too, about the amount and kinds of group experience a child has had. We want to know about his emotional responses and about ways parents have used to manage his behavior. If he has been in school, we want information about his adjustment, behavior, and learning in the school setting.

Trial periods are awfully important in determining how well a child can adapt to a group situation, whether it is a day activity center or a school program. The chief trouble with trial periods, for retarded children, is apt to be that they are too short. A period of a month is just not adequate to serve as a basis for judging that a child cannot adjust in a new situation - although it is true that there is sometimes a child who simply can't be handled in a group situation long enough to permit a really adequate trial. In general, we have felt that a whole school year is not too long, if the child can be managed at all, even though he requires much extra attention and supervision. Nor is the fact that a child fails to adapt in one group adequate evidence that he would not be able to adapt in another. Sometimes groups have to be "juggled" quite a bit before optimum placements are found.

Throughout the training period, we will be talking about the whole range of retardation problems: The child, the adolescent, the adult; the higher ability educable, with limited potential for academic learning but considerable potential for near-independence as an adult; the lower ability trainable, with capacity for developing fairly adequate skills for self-care but limited likelihood of adult self-support; the "total care" ability level and the needs this group has for security and protection. We will be considering all kinds of programs we know something about - nursery school, day care programs, special education programs, vocational programs, sheltered workshop programs - and trying to see what things are needed which are not now available. We will be concerned with legal

and governmental aspects of the problem and with economic aspects as well. We will be thinking about both the professional and the practical aspects of problems. It is a big field, and an expanding one. Learn all you can.

SIGNIFICANT INTERACTION OF OTHER HANDICAPS:
SENSORY, MOTOR, PHYSIOLOGICAL, SPEECH, SEIZURES

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I would like to begin by telling you about Howard; this is not his real name, of course. Howard is 17 years old. Early in his life he was described as mentally retarded, borderline defective range, and at about the same time, the physicians discovered that he also was a victim of muscular dystrophy, a progressive neuro-muscular disorder leading, in the most severe cases, to complete helplessness. This combination of difficulties will illustrate for you some of the problems that we will discuss today. Howard is confined to a wheel chair; unable to take care of his own toileting, feeding or propelling himself around. He does not have the strength in his hands to turn the pages of a book so that he can read. He can barely talk audibly and his speech is extremely slow. He can read, though not as well as might be expected. It's a little hard to know whether or not he wants to read. Since this is probably one of the few remaining things that he could do to pass the time and entertain himself, it seems tragic that he does not read better. The interaction of two things makes evaluation of his present situation and planning for him extremely difficult. . Perhaps he could function at a better level than he does academically if he were not so severely handicapped physically. On the other hand, if he were brighter than he is and better motivated, it is possible that mechanical aids might 'be devised to make it possible for him to do more.

Then there is Tommy. Tommy had an older brother who was diagnosed at age five as being mentally retarded, entered in a regular kindergarten and after some time was found to be deaf, a fact which had been completely missed. In subsequent intelligence testing, he earned better and better scores and this boy is now functioning within the normal range in a class for deaf children. When Tommy was studied, naturally the possibility that he also was deaf had to be considered. After several evaluations, it is now quite certain that Tommy is both hard of hearing and mentally retarded. Now the questions that this child's situation raises are as difficult as those faced with Howard. Where should Tommy be placed in school? Should he be placed with hard of hearing children or with retarded children? How safe are the predictions that can be made at this time about his final intellectual level? What will he be able to do educationally or vocationally? Can a retarded child learn to lip read? Lip reading is not an easy thing to learn; not something that can be done without good motivation, good training and an interest in what's going on. If Tommy cannot be taught to lip read, how can he communicate with others? How certain are the estimates of his level of retardation?

These two cases illustrate the problems of evaluation, education,

and prediction about which I will talk in more detail. It is a sad fact that the problem of multiple handicaps is not dealt with as such in the literature that is available to us. I ran quickly through the books on special education in the library and found no book that devotes so much as a chapter to this problem. Some make a fleeting reference to it, but most of them not even that. Yet the multiply handicapped present most challenging and complex problems, both to the diagnostician and to the educator.

You have heard something about intelligence tests, how they are used, the growth of intelligence and so on. The first point I want to make is that adaptation of procedure and test material is not only permissible, but necessary in working with multiply handicapped children. Though we have standardized procedures and expect to use them when we can, the problem is that when any avenue of response is cut off, it necessitates adaptation of the material in some way. Adaptation must be done, and the implications for recommendations made therefrom. We can't make the same assumptions about tests that have been adapted to a child's handicaps as we can about those given in a standardized manner. The second point is that observations by psychologists, teachers, classroom assistants, parents are extremely important in the evaluation of multiply handicapped children. Knowledge, therefore, of child development principles and child behavior is extremely important in order to evaluate what we see. The third point: qualitative aspects of the test performance itself are very important. Sometimes scores are impossible to get and the psychologist must make a statement based on the qualitative aspects of a child's performance. Experience with normal as well as handicapped children helps to keep in mind the base line of typical behavior to use as a standard of comparison. Tests are selected and adapted to get around, not to reduce the effect of the handicap. They should elicit responses from a child in all areas of behavior in which he can function so that general estimates can be made. We do not, for instance, want tests that would be an advantage to mentally retarded children because we are trying to assess the deviation from normal. Tests are adapted and selected so that the child has an opportunity to express everything that he has, but not to destroy the effects of the limitations of his handicap.

I will begin the discussion of specific disabilities with cerebral palsy because a larger percentage of these children are mentally retarded than is true of any other handicap. Most studies show that at least 45% of cerebral palsied children are retarded to some extent. The difficulty of evaluation increases in direct proportion to the severity of either one of the handicaps; that is, the more retarded the child, the more difficult it is to be sure that a good estimate is obtained. The more physically handicapped the child, the less the confidence that can be placed in the results of testing. A mildly palsied child with a mild retardation is not such a difficult problem. Tests of normal pre-school children depend very heavily on motor development and sensory responses. These two avenues of expression may be unavailable to cerebral palsied children and thus the test taps

too narrow a range of behavior. Therefore, the tests for normal children, adapted for use with handicapped children sometimes give us very little. If a young child cannot use his hands, cannot walk, and has no control over his head, the psychologist is limited in the kinds of things that will help evaluate the child's thinking. We often need to adapt test material for the child who has no use of his hands. Occasionally only the movement of the child's eyes can be used as a sign that he comprehends what is going on. Speech, of course, is often very impaired, sometimes absent altogether. You have seen the Merrill Palmer material - the boxes and form boards and that type of thing. If the child can use his hands, this is a useful instrument because no speech is needed; demonstration is used to get him to do what he is supposed to do. However, if the child cannot use his hands, a picture vocabulary test is helpful. There are cards with four pictures and the examiner says "chair" - then the child is to point to the chair. Now, if he cannot point, he may be able to indicate the right picture by the direction of his gaze. If his head is so spastic that he cannot even do that, there may be a finger that he can raise for yes and another one for no. The examiner points to each picture and the child makes a motion of that sort. One caution about the interpretation of picture tests is in order. When children are so severely handicapped physically that they cannot do anything, they have probably also been pretty limited in their experiences. They haven't been out as much as other children and as the pictures become increasingly difficult, they soon depict things that he really has not had a chance to see, although he is old enough to have done so if he were not physically handicapped. The Columbia Mental Maturity Test is another non-verbal test in common usage. It has less predictive value than the picture vocabularies, but the idea is so good and the material is so attractive that it is often helpful. It requires the child to make discriminations, very simple at first and then increasingly difficult, finally involving more than one concept. The test does differentiate ability to some extent, there is no doubt. I think the only care to be taken is not to use it as predictive of success in school learning because it is not closely related to progress in school.

If the child has some speech, there is general agreement that the Stanford-Binet is the best test to use, particularly with young children. At the early levels, there are many motor tasks that the child will not be able to do if his hands are not usable, but there are also verbal items. Most psychologists adapt the Binet as much as possible.

When every device has been used, including the psychologist's observations, it is possible only to make what we call an educated guess, rather than a definite statement about the child's ability. However, as I was looking through some of the literature, I found that various studies report that in 90% of the cases of cerebral palsy children, an estimate of the child's ability can be made. As I think back about my own experience I think that is probably right. Studies

also show that when the psychologist makes an estimate he is apt to be right in 75 to 80% of the cases when compared with the child's school progress the next two years. However, when evaluating multiply handicapped children, it is better to err on the side of optimism because when a valid test cannot be obtained, the only possible thing to do is to enter the child in school and see what he can do. Tests after all are intended to be predictive and shortcuts of what the life situation would establish anyway, so that if testing is impossible, the child should have a chance to show what he can do.

Let us talk next about hearing handicapped children because this is the next most difficult category. An interesting thing that is bothersome and it points up, I think, why the diagnosis here is so difficult is that there are many signs of hearing loss that are also characteristic of mental retardation and vice versa. For example, a retarded child and/or a deaf child may be characterized by delayed speech. Lack of response to the spoken word could be due either to deafness or retardation. Lessened laughter is another sign of either defect. A child who does not respond to humor, see a joke, or laugh might be either deaf or retarded or both. Head banging is another characteristic of both deaf and severely retarded children. Imitative play rather than creative play is characteristic in both groups - the deaf child because he doesn't hear instructions or hear what people say and the retarded child because he hasn't the ability. He is more apt to imitate because he doesn't think of his own innovations. Temper tantrums are also common partly out of frustration and lack of communication in both cases. In testing young deaf children, the Merrill Palmer can be used. As you noticed, the items are manipulative and problem solving in a non-verbal way. Demonstration is used and the material is so attractive that even though the child is flighty and inattentive, he will usually enjoy it and stick with it. The material seems very much like play materials that can be bought in stores - you probably noticed that. This means that many children have had exposure to some of the tasks. When a totally deaf child performs within the normal range on the Merrill Palmer, it is my impression that he is at least within the average range or has had very good experience and training at home. When a deaf child cannot do the tasks at his age level in spite of demonstration and possible previous experience, then it seems reasonable to say that he is probably retarded. This, of course, assumes that he is cooperating. With older deaf children the Arthur is a good instrument. This test has a lot in common with the Merrill Palmer scale. It was developed for use when it is necessary to minimize communication problems, either with deaf children or others who do not communicate verbally. It is intended for older children, but is made up of form boards, picture tasks, and other performance items. The instructions are given in pantomime so that no language is needed. Another test in common use with deaf children is the Nebraska scale. It is for school age children and gives us a measure of school learning ability rather than an IQ. It too is completely non-verbal with directions given in pantomime. The major adaptation in the testing of the deaf children is in the use of pantomime and gestures. Now, this sometimes presents

a problem in interpretation to parents and sometimes even to teachers. If a parent observes the testing of a young deaf child, the parent may say that the child could do the task but that he did not understand the directions. Part of the measure of intelligence is comprehension of direction; therefore, if the child cannot do the task, it is not crucial whether that is because of lack of comprehension or lack of ability. It may be some of both, but it is important to interpret to parents that a normal child would understand this **pantomime**.

Visual handicaps coupled with mental retardation also call for some adaptation of test material. Obviously the necessary adaptations here are to eliminate the visual cues. If the child is known to be visually handicapped when his intelligence is measured, certain techniques can be adapted. Fortunately for us the causes of blindness are not so likely to be associated with other factors that would also cause retardation. The average intelligence of blind children throughout the city is within the average range, in contrast with the deaf or the cerebral palsied. However, occasionally a severely retarded blind child is seen. With young blind children, we are dependent on observations of their behavior, their play interests, response to verbal cues, tactile and auditory cues, curiosity about what's in the world about them, comprehension of directions, interest in new activities, and memory; these are all very important in evaluating a young blind child. However, many blind children have been extremely over-protected and in such cases capacity to interact with the world around him is very much reduced. Blind children who have never been allowed out of their cribs or playpens have not developed an interest in a bigger world; many have fears and extremely inhibited behavior. Therefore, observations must be accompanied by a knowledge of what the child's experience has been, how he has been handled and how much chance he has had to develop normal behavior. An adaptation of the Stanford-Binet has been made, called the Hayes Binet, which is really only a combination of the verbal items from two forms of the Binet. This is the test of choice with blind children when possible. A blind child is also asked to handle materials, name objects, answer questions about the family, about names and ages of siblings, about activities. To some extent this taps his comprehension of the world around him. Older children can be given the verbal section of the Wechsler Intelligence Scale for Children. The WISC is an intelligence scale for children which has a performance section and a verbal section. The verbal section is rather highly related to academic learning but it is useful with older blind children and the correlations between it and the Binet are good.

The combination of mental retardation and seizure patterns should also be mentioned. The choice of tests for children who have seizures is dependent entirely on what else is wrong with the child. The main problem in testing a child who has seizures is how often he has a seizure while being given the test. Petit mal seizures are often first seen by a psychologist who is giving the child an intelligence test because somebody thinks he is retarded. This happens because

the psychologist sits with this child in a close, direct relationship for an hour or more and if the child is having very many petit mal seizures, he is likely to have one during that time. Sometimes the seizure would escape notice in a more general group situation. If petit mal seizures are known to exist or if they are seen in the process of testing, the psychologist must be sure that the child hears directions; must repeat directions if needed and, in interpreting results, must take into account the possibility of seizures having occurred. Interpretation of test scores of epileptic children, particularly if they are also retarded, should be made with great caution and not until repeated measures have been obtained. The combination of mental retardation and seizures is very common and these children, as a rule, appear in any group where there are retarded children. The hazard is less in diagnosis than in long range predictions about these children.

Speech problems should also be mentioned. Everyone who works with retarded children or cerebral palsied children becomes very adept at understanding un-understandable speech. However, sometimes speech is absent altogether and sometimes it really is unrecognizable, so that the most experienced people can't make out everything a child is saying. This, of course, in relation to mental retardation means that the tests given should be those that do not require speech. Here the Merrill Palmer, the Arthur, the Cat ell and the Peabody are again useful. With older children, the performance section of the WISC is indicated. Some children with severe speech problems will inhibit speech altogether because they are self-conscious about it and will say they don't know rather than attempt the difficult process of trying to express an idea.

A sixth category of overlapping defects is Central Nervous System (C.N.S.) disorder and mental retardation. It is a difficult one to go into because it is such a broad field and one that we don't know enough about. Mental retardation as well as each of the aforementioned defects is often accompanied by some degree of cerebral damage. The evaluation of these children and prediction of their future development are extremely difficult. One reason for this is that we don't know as much as we should about the functioning of the brain; some defects get better without any apparent reason; some symptoms don't and it is hard to know which is which. Interpretation to parents and even teachers is also very difficult. Parents will grasp very gladly onto somebody's statement that a child is brain damaged rather than face the fact that he is retarded; the fact may be that he is both, and as far as outcomes go, it doesn't make much difference. Observations are very important, particularly with young children. In addition to test observations, the observations of parents and teachers regarding hyper-activity, tremors, poor coordination, balance, sleep disturbances and such are all very important. In the test situation perceptual difficulties are of particular interest. Examples are items in which the child is asked to pick out the one of several objects that is different than the others. Visual-motor problems are noted: the average five year old child can draw a square, for instance. Many

retarded children cannot until a later age. However, a seven year old child who is retarded and can do everything else at the five year level might not be able to draw a square because he can't make the connection between what he sees and the motor task of putting it down on paper. Coordination problems and directional or laterality problems are often seen: the little boy who writes his name from right to left and backwards instead of the way that most of us do. Ambidexterity is often related to brain damage; so too are memory problems and perseveration, which is a word that means being unable to stop doing something. An example of that lies in drawings of a little girl, who when asked to draw a man, drew men clear across the page until she ran out of paper before she could stop. These things are aspects of behavior that lead to the suspicion of cerebral damage possibly in combination with mental retardation. Sometimes the defect is in development and improves with age. Sometimes it does not. When the child is also retarded and the C.N.S. defect does not improve, the educational problem is severe.

Perhaps I might say a little about educational problems. A later talk will include more about educational planning but diagnosis is a sterile thing unless it is done for a purpose such as to determine whether the child can go to school and what kind of a program he should have or what kind of a job he can do. Therefore it is difficult to talk about evaluation without going into the practical application of the findings. Educational provisions for handicapped children cost more per capita than educational programs for other children. When the child is multiply handicapped, the cost goes up, of course, very greatly. Some of these children need very small groups, even as small a group as three or four. Some of them are even taught in individual instructional situations. This is a very costly thing and it raises in the minds of educators and the diagnosticians some very serious ethical and practical problems about the use of money - how much money is enough to spend on a child and how can it best be used? Are the evaluations and predictions made about these children adequate, so that the expense can be justified? When should the effort to teach a child academic learning be ended? How can the decision be made that a child has gone as far as he can in learning? What kind of provisions are needed for multiply handicapped children? Who is going to teach them? For instance what kind of a teacher is best able to teach a retarded deaf child? If it can be established that the child is retarded, it is generally agreed that the teacher needs to be trained in the education of retarded children because this is the primary handicap. Intellectual limitations affect everything else. But should we establish special classes for every possible kind of disability? If a special class were established for every combination of mental retardation and one of the other handicaps, the total would be 21 different kinds of special classes. Some of them would have only three or four children in them. In addition, there are children who have more than two handicaps: blind, deaf, retarded children or blind, deaf, crippled retarded children; the combinations are unlimited and the solution of a special class for each category seems impractical. Yet, neither our

educational facilities nor the literature which either follows or leads the services, copes with the problem of educational planning. One possible solution might be to establish classes on the basis of criteria other than diagnostic categories. Age would need to be one criterion; functioning and behavior, regardless of the reason for the child's functioning, would be another. Thus, there might be many different diagnostic categories in one group, but all of them there because they function together in a way that a teacher can handle as a group. We have made some advances in that type of program when a child who is not retarded has been placed in classes for retarded children because he fits there and works well with the group. This would make possible much more flexibility in what could be done for the children. They could be moved from one type of class to another where the group or the program was more suitable. It would also lead to a much more experimental and adaptive approach on the part of teachers. Teachers of both normal and retarded children are frightened of handicaps that they do not understand. If a teacher of a special class is asked to take a child who is blind, her immediate reaction is one of anxiety. She does, however, know a lot about children; the blindness is something she can learn about by taking the child into the class and finding out what he can do, going on from there, with help, of course. It is not practical to train people in such specific ways that they feel they cannot cope with any other kind of child. I think that flexibility in all educational programs is essential.. It seems possible that a flexible program would actually be cheaper to run and would eliminate *some* serious problems.

In summary, I would like first to emphasize the importance of observation and experimentation, both in diagnosis and program planning. Second, the fact that interpretation to parents is complicated by multiple handicaps seems obvious. It is understandable that a parent would find it very hard to accept a diagnosis of mental retardation if cerebral palsy or brain damage can be used to explain the child's problems. Thirdly, the use of wide ranges of ability in prediction rather than too specific ones is wise. Fourth, it is best to make short term plans rather than long range ones for these children. Knowledge increases, children change and facilities improve; the immediate situation must be dealt with, but long range plans are subject to frequent change. Lastly, I approve of a reality orientation in evaluation and planning. Tests are intended, of course, to bring out the very best that the child can do - his very top potential. It would be very fine if society were so advanced that this is what it also could use or want, but unfortunately it isn't. Society's expectations are built on the realities of employment, facilities and services for handicapped people. Therefore, the child's actual functioning: what can he do as society now exists is the reality that needs to be faced. It will matter little to the individual if the psychologist believes him to be brighter than tests show, if his other defects prevent his use of the intelligence. If Howard, for instance, were less retarded than he is, he would still be vocationally unemployable because there is nothing he could do other than entertain himself with the help of a

mechanical device to turn the pages. If Tommy were not deaf, his retardation would severely limit the kinds of gainful employment that he would be able to find. The diagnostic techniques tap maximum potential, but society cannot always make maximum use of it.

EDUCATIONAL ASPECTS

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There are speakers who have preceded me, of course, and I don't know how much I may duplicate things already said. Perhaps the best way for me to proceed is to talk as though I were someone planning school programs for mentally retarded children, since that is what I am, and reflect the kinds of things which school administrators consider when they plan school services for retarded children. We can try to indicate how these considerations relate to the roles that other people or agencies may be fulfilling in their work with the retarded. We are most appreciative if people working with the schools understand what the schools are aiming to do.

I must preface all comment by noting that all school systems do not organize and operate in the same way. However, there are certain educational premises and certain principles regarding the rehabilitation of mentally retarded children which have sufficient acceptance to lead different agencies to gear their practices and program planning to insure the continuum of alternatives needed to accommodate to various degrees of disability and complication of handicap.

We now have federal legislation which is feeding money into service channels. Qualification for these funds requires state planning under the aegis of state Mental Retardation Planning Councils. These councils are feeding into the stream of thinking a more common point of view. Because this planning involves design of services for the state as a whole, there must be some agreement on the rationale behind recommendations.

Starting from this point, then, what kind of rationale do we use in our planning within the school system?

I would like to bring out several points in passing. One is that we define handicap functionally, not by test score alone. This, I think, is a significant change over a period of time. Programs for the mentally retarded started in the city of Minneapolis back in 1912. Classes for the mentally retarded did not develop under any coherent rationale of what special education was all about, what mental retardation was all about, and what the objectives of special classes were, and so on. Following passage of the 1957 special education law under which we presently operate, a department of special education was established at the state level. We then began to develop a more consistent interpretation of the legislation which enables the special education and vocational rehabilitation programs.

In Minnesota, the programs of special education and rehabilitation are headed by the same commissioner. This may sound like an insignificant element, but if you are working in an administrative position it becomes an extremely significant factor in implementing concepts. The State Department of Education begins by setting up regulations, certification requirements, and so forth which are supposed to further the intent of the law.

Rationale makes its first entry at the level of legislation where we have worked right into the law itself the concept that handicap is a relative condition, a functional disability, operationally defined relative to a frame of reference. The extent to which a condition is a handicap changes from time to time with changes in medical knowledge, with changes in social conditions, with the kinds of services that develop and with the way the regular educational program is operated. The latter contingency is particularly significant to school-age children.

People considered the blind ineducable until Louis Braille invented the braille system. The technique changed the status of the blind to one of being educable. The technology available, then, influences the definition of handicap.

There is another concept which feeds into modern special education planning to a greater extent than previously. That is that special education and special classes are not synonymous. We are now trying to design special educational services so that programs can be custom tailored to fit individual needs as carefully diagnosed by qualified people trained for this kind of work. So, we think not just in terms of special classes but in terms of a broad range of service alternatives which are needed to improve the adjustment of the individual.

In all educational planning for the handicapped we speak of education for life adjustment without embarrassment. Life adjustment may be "fighting" words to the proponent of traditional definitions of education, but it is the heart of special education. We feel that what we should be promoting in special education and rehabilitation is independent functioning. The handicapped are trying to adjust to social systems which presume "normal," independently functioning people in a free society who, for the most part, use the schools and whatever social training they receive in the home to achieve a level of performance which will permit them to compete in the society in which they find themselves. In our society, we must take into account that we have a society and an economy that is based on work as the means of distributing wealth. This is a very important factor as far as the mentally retarded are concerned. If our society were not based on the work ethos, much of our work with the retarded would be different.

At the other end of this dependence-independence dimension we have the people who are extremely dependent, those who have so little capacity for self-sufficiency that custodial care is required. For these

people we have health and welfare services, we have institutions, we have hospitals, and we have various kinds of community facilities to provide them care and protection. Special education and vocational rehabilitation represent a zone of defense which is directed at helping people to become as independent as possible.

School services, then, are planned with a number of benchmarks in mind: one is that the niche the person is to fit into is as important as the disability itself and that the "niche" changes. This is why the introduction of automation is so important to education of the retarded. It cuts out many low skill jobs which these people might have been able to fill. For school-age children, the frame of reference against which they are judged is the curriculum and rules of the school. In the school setting the retarded tend to be those who can't meet achievement standards in academic areas. We can too readily assume that this means they can't meet achievement standards in other realms of life adjustment, such as the world of work.

Another point of extreme importance in educational planning is that among public serving agencies, the school system is the most non-selective agency. Public schools are supposed to make education available for all children. We have no choice when people show up at the door. We are supposed to serve them. If we don't serve them we must explain why not. We must have very firm procedures for documenting that a youngster cannot be served. We must be able to justify exclusion or denial of service, even to the point of being taken to court, because the school has a mandatory, legal obligation to the client which few other agencies (except correctional institutions) have. This puts educational people in a peculiar position relative to the people they serve.

The client may not want to come to school and we may not want him, but we are stuck with each other. This brings in many problem elements when it comes to such issues as counseling with parents, trying to influence child behavior through relationship techniques, and so forth. We cannot say, "We have a service here and you can use this service if you abide by certain conditions," because we are not really in a position to set conditions. We sometimes act as though we were and "get away with it" because we have purposes in mind, but if someone really wanted to challenge us on it, it might be rather difficult for us to defend our position.

Because we are non-selective in the population that we serve, we capture in our retarded groups a broader representation of what is represented in the condition of mental retardation than would be found in any other agency which is operating on a public or private basis. A research and demonstration project that you have probably heard about (Project 681) did a scatter-plot to test certain relations. On a map of Minneapolis we have drawn boundaries along census tract lines which define the area of town in which the delinquency rate is over 63/1000.

This area of high delinquency is the same area of the city in which family incomes are lower, unemployment rates are higher, families move more frequently, and so forth. We find that 65% of the Minneapolis special class students live in this disadvantaged area of town where 27% of the juvenile school age population lives. Obviously, we are drawing our "mentally retarded" disproportionately from certain areas of the city. The typical membership of parent organization concerned with mental retardation are not representative of the social-economic level of the major portion of our special class students. We keep stressing that mental retardation can strike any family at any level and, of course, it can, but apparently families fit certain socio-economic levels are "struck" more frequently.

We can be grateful for the level of competency represented in our parent groups. They have become a tremendous social force in developing understanding of the problem and helping us to achieve improvements in services. But, if we are talking about parent education and are content if we reach the organized parents we, in our situation, would be missing most of the parents. We can test the relationship another way - by looking at the occupations of the fathers of our special class students. This slide clearly shows the predominance of occupations at the lower social-economic level as compared to the occupational distribution of Minneapolis males. In Minneapolis, 23% of males are in professional and managerial positions. Among fathers of the retarded we see a dramatic reversal. These are things which must be adapted to in educational programming for these students.

If we compare the performance of these special class students on "verbal" intelligence tests and what we label as "performance" measures, we find that many would be retarded by one measure and not by the other, if test score were the defining criteria. This slide shows the striking difference in the range of IQ scores on verbal and performance measures on the same sample of special class students.

We must then, look at a special class population such as ours and recognize that what we have is a group that started out in regular class, for the most part, and failed to keep in the stream. We don't have in our special classes all of the youngsters who would qualify as being mentally retarded on the basis of abstract criteria which might be set up, such as 50 to 80 IQ. We have only those that the regular educators said they couldn't educate in regular class. There are many "test score" retarded in the regular classes who can get along there, who adjust well there and who are acceptable there.

The most distinguishing factor is reading achievement. Those who wind up in special class are those who don't learn to read very well. Our special class students average fourth grade reading level by the end of their school careers. Some do much better, but some are still at a primer level. Since their average IQ is around 75, we would expect better achievement.

It is generally conceded that it is difficult, if not impossible, to diagnose, case find, or define the Majority of the educable retarded at the preschool level. We simply don't have the means to do this nor are all those who will later fall in the educable group test in the educable range at preschool ages. This is because of the nature of the development of intelligence. It takes some years for some of them to become that retarded when certain forces are operating. So in the school situation the average IQ in special classes increases as we move up the grade levels. You will note that the average IQ at the elementary level is 69.5, 71.7 at the junior high level and at the high school level 75.9. By some definitions of mental retardation all those above 75 IQ would not be classified as mentally retarded. We would expect better reading achievement than we find from a group at that IQ level. All of these factors must be taken into account in school program planning, in social planning, and in prediction of vocational training needs and the work adjustment of the retarded.

Our planning needs to take into account differences in verbal and performance ability. When we look at the relative ability of our special class students on such measures we conclude that performance ability doesn't give you much help in the kind of curriculum that the Minneapolis school system provides. Apparently reading and verbal skills are much more important to school success. The student may have talents which would have value in another circumstance but they aren't very useful in this one. So the student gets to be defined as retarded. But perhaps these talents may be valuable and useful in the work situation. Possibly it is because different sets of abilities are used in the school and work situations that follow-up studies find quite a number of the pupils defined as retarded in the school situation fade into the crowd once they get to be adults. Once out in the world labels are less often applied and no one thinks of them as retarded anymore. They are using in their adjustment abilities which were given no value in the school situation. We keep generating what optimism we have from the material undervalued in the typical school setting.

In our program, we try to be alert to all the forces contributing to retarded performance and help the retardate alleviate them, not just through our own resources but through cooperation with other agencies. The needs of many of these students go beyond what the schools are able to do. Hopefully, by trying to establish close and understanding working relations and cooperative programs with other agencies we may be able to compensate for some of the limitations of their experience.

For example, Gordon Krantz entered the cumulative records to determine how many of the youngsters came from families which were broken throughout the child's school career. We find here that special class students come from broken families more frequently than do regular class graduates and, I think rather interestingly, even more frequently than do high school dropouts from regular classes. Among Minneapolis regular class students 85% grew up in families normal

throughout the student's school career. By contrast, in Minneapolis special classes only a little over 60% came from homes normal throughout the child's school career.

Under a functional definition of mental retardation, that is that of not being able to fit in the establishment, and meeting certain criteria of psychological evaluation, we have identified a group of youngsters whom we proceed to call mentally retarded. We are aware that under these defining standards we have collected a most unhomogenous group. Each member will need a different kind of management. The problem is complicated by the fact that youngsters find their way into the special classes at different ages. The better ability youngsters may get along relatively well for the first three grades, but after that things are likely to get rougher. When a student hasn't learned to read, it becomes very hard to successfully negotiate the hurdle from third grade to the fourth grade.

We have tried to break the problem down into sub-classifications to clarify what has been captured in the broad category of retardation. We have done intensive studies on one age level group using a variety of measures, observations, medical examinations, social histories, et cetera. We conclude that about 25% of the special class group seem to show uncomplicated mental deficit, about 18% mental deficit with complications, another 9% are probably dull-normal rather than retarded, another group seem emotionally disturbed and/or socially maladjusted, 19% sub-culturally disadvantaged, 11% were sub-culturally disadvantaged plus disturbed, 4% organic brain dysfunction, 10% some kind of handicap or block, 4% were unclassifiable. Obviously, a wide range of disabling conditions are represented. Educational and social service must be adjusted to this diversity of need.

A recent bulletin of the Vocational Rehabilitation Administration reflects the thinking of participants at a conference in Wisconsin in November of 1964. Professional people deliberated for days trying to write a definition of mental retardation which would fit the realities. Some statements suggest all too categorically that most mental retardation is the direct result of cultural disadvantage. While we recognize the influence of environmental conditions during critical growth periods, some statements seem to imply that environment is the singular causative factor.

Undoubtedly a complex of factors is at work. One-third of the mothers in cities of over 100,000 population are medically indigent and receive little, if any, prenatal care. The rate of premature infants is higher in this group. Infant mortality is high among prematures, and handicapping conditions occur 50% more frequently among premature children. This complex of disadvantaging factors must then be expected in a public school special class population, making it essential that we place youngsters in the setting on the basis of where they will get the service they need rather than on more arbitrary criteria such as age or IQ.

The complexity of the condition of retardation becomes a crucial point in the establishment of social policy and setting the course of social action. For example, in designing the legislation enabling day activity centers it becomes important to maintain enough flexibility so we do not exclude from the day activity center a youngster with an IQ of 58 or 60 who is of school age, if that center is judged to be the place for him to be. It is essential to define facilities and the legal structure under which programs operate so that the spectrum of services is complete, with sufficient overlap among the services offered under various agencies so that people can be moving in and out as needed. It is necessary to keep evaluating constantly to insure that people are receiving the right service.

We have a relatively large program, I suppose, although certainly not as large as the larger cities. We usually serve about 1400 pupils a year in our special classes for the educable retarded. Our Board of Education voted to assume responsibility for the trainable retarded just last June, so we are only now beginning to enter full programming at that level of disability. For a number of years we provided only trainable classes here at The Sheltering Arms, which were experimental in nature. Their purpose was to test whether or not education seemed to have a role in serving this level of disability.

In the distinction between trainable and educable, as in other distinctions, we do not go by IQ alone. The important determinant is function. This position presents tremendous public education problems and a considerable parent education problem. I regularly receive calls from parents who insist that because their child has an IQ of 52 we must place him in an educable class because the law says so. We must then explore with them the real meaning of some of these concepts.

We believe parent counseling to be a most important aspect of programming and that agencies must work together in common directions to communicate consistently to parents and the public at critical decision points. What parents expect of a particular child and what parents will accept and support so that the youngster feels comfortable in the situation will depend to a considerable extent on how realistically they perceive the issues. We feel that it is important to work with these parents all through the pupil's school career. We see preparation for work as a developmental process which starts on the first day that we have assumed responsibility for the child or when he entered school. We keep trying to shape him in the direction of becoming economically independent and self-sufficient to the greatest extent possible. If the day comes when two percent of the population can supply all the goods and services the population needs and we have a way of distributing income without work and everyone is on a "right to live" grant, we will have to change our program to meet this new concept of living. Until this time comes, we say that since work has the value and meaning that it does in our particular culture, work for pay is important to the retarded individual because it reflects back on his feelings of self-worth.

There is some difference in the way that vocational rehabilitation has traditionally approached the problems of service. Public schools must serve an educable individual whether he is expected to contribute anything to society or not. We are educating many crippled children that we know will probably never be able to work. We are a service institution, so we serve. We do not have built into our considerations the same concept of "feasibility" for service that Division of Vocational Rehabilitation does. Special education does not rest its case on whether the individual is likely to pay back in taxes what we have invested in him.

We have many ideas about what we would like to implement, and accept the principle that we are a service agency, that we do have responsibility and we do want to carry out our responsibility, but we are up against the persistent reality of insufficient funds, not enough staff and inadequate facilities. Consequently we too create our own kind of program "fall out." This is probably unavoidable and some cases should fall out of public school special education programs. Some are better served in a residential setting away from the performance-depressing forces generated by pathological conditions in the home. There has to be constant effort to improve the articulation of programs under different agency administrations.

Special classes for the educable retarded are usually located in regular school buildings along with classes for normal children. We like to have two or three special classes in one building. We think this provides for a better organization, and it's administratively advantageous, too. The special teachers can then do things together and feel less isolated. We have to fit the pattern of the 6-3-3 organization of the school system itself. •

Classes operate as self-contained classes at the elementary level. That is, the classes are taught by an individual teacher and the children stay with this one teacher all day. They may go out for gym or some other activities with some of the other students, but such integration is not extensive. At the junior high school level, students stay with the special class teacher for about two or three periods, during which time they concentrate on the more academic work such as social studies, English, and so forth. They are scheduled to regular classes for such subjects as physical education, industrial arts, home economics and courses of this character. This pattern of programming continues through the senior high school level.

This is the "traditional" pattern. As a result of the curriculum studies and data on outcomes coming from Project 681, we are now examining the adequacy of this organization and the appropriateness of the curriculum content itself. We discovered, for instance, that though a three-year period of high school level programming was, theoretically, available to all special class students, only about one-third of them completed that many years of school. This suggests that the expectancies set up by the system were too much for them to cope with so many of them either dropped out or were "squeezed" out.

So now we are considering to what extent some of these opportunities should be modified and how they may be more suitably adapted to the needs of some of these retarded youngsters. He found certain junior high school students could not take the complexity of demand which exists in a typical junior high school. For example, going from room to room period after period, knowing where their lockers are and remembering the combination to their lockers, getting there on time, and so on, is too great a demand. We have, therefore, started in the direction of having a two-track program at the secondary level, with one track conducted essentially on a self-contained system. It has been interesting to see that in the three years since we have instituted this practice that the fall-out from that system has been much lower than the rate of fall-out from the traditional organization with its sequential period programming.

Judging by the vocational goals of the project, we become more and more convinced that the hypotheses on which the project was based were tenable. When we analyze why students lost jobs, we seldom find that they lost jobs because they were not able to do the job. This finding is, of course, conditioned by the fact that we had placed them on jobs within their ability range to begin with. They lost jobs for such reasons as not showing up for work, not attending to directions, and so forth. Attitudinal and responsibility factors, or rather, the lack of them, were critical. Consequently, we think we need to place more emphasis on social adjustment, on being able to carry tasks through to completion and persisting in performance. This orientation subordinates some of the academic teachings which many people in education regard as transcendently important.

When we read studies such as those which try to judge the usefulness of special classes by comparing the reading achievements of students in special classes with retarded educated in regular classes, we find it hard to be impressed. Only limited conclusions can be drawn from the finding that the retarded educated in regular classes achieve at a higher reading level than the retarded educated in the special classes. We know that unless cases were randomly scheduled, those who had the most trouble learning to read would be the ones most likely to be placed in special class. Many of them have a specific learning disability along with their general retardation. Also, there are several other bits of evidence which indicate that the social adjustment of the retarded educated in special class may be better than that of the retarded remaining in regular classes. There is evidence from sociometric studies that retarded youngsters in regular classes tend to be socially rejected by their normal peers. It is difficult to measure the effect of such rejection, but these are all reasonable issues to consider.

When we look at the children in the special classes we may get the impression that many of them do not seem to be terribly retarded, and that may well be right. We begin to wonder, then, how good a job we are doing, how these youngsters are doing in the world, and in what

was we may need to modify the curriculum to take advantage of their better abilities, So we conceived the idea of applying for a grant from the office of Vocational Rehabilitation to help us do a number of related things simultaneously. First of all, we wanted to do a follow-up study of some of our former special class students to see how they were getting along. If they were the relatively bright retarded population, as they appeared to be, how well were they coming out in economic self-sufficiency and social adjustment. We wanted to see whether we could improve their employability through various means of training; we wanted to know what dimensions of behavior we would have to try to work with and in what directions to modify the special education and vocational rehabilitation effort. We were also concerned with how we might procure more adequate vocational rehabilitation services for our students.

We have had a Branch Office of Rehabilitation as part of our organization since the 1930's. That is why my title is Consultant in Special Education and Rehabilitation, Within this Branch Office, one of the counselors was supplied by the school system (with some financial assistance from the Division of Vocational Rehabilitation) and two of these counselors were employed by the Division of Vocational Rehabilitation. We had, then, three counselors working with the Minneapolis school population. It wasn't very hard to see that there was quite a bit of job turnover in the two vocational rehabilitation counselors supplied by the Vocational Rehabilitation agency. Furthermore, parents were often calling to complain that their retarded youth were not receiving the service hoped for. Upon investigation it frequently turned out that there had been employee turnover and the new counselor was having to become familiar with the case load and pick up the threads. It was apparent that there was much greater stability in the counselor employed by the school system. Looking at these factors, it seemed as though either the whole organization was wrong or what we needed was not one counselor employed by the Minneapolis Schools but three. This would be a pretty hard proposition to sell a school system, however, because they would feel that they were being asked to supply a service which was the responsibility of another agency. The schools have more than they can do to carry on their own educational responsibilities without assuming the responsibilities of other agencies.

There is another critical point involved, that is that it is obvious, when you are dealing with a complex problem such as mental retardation which has existed from birth and affects all learning, that preparation for work is a developmental process. Preparing such a youngster for work may take some time. He doesn't catch on very fast, and all of the inappropriate attitudes learned over a long period of years are not likely to yield readily to verbal counseling that covers no more than a few hours over a relatively short period of time. It seemed reasonable that there would need to be other ways of proceeding with this problem than the traditional practices of vocational rehabilitation, which have been geared largely to restoration

of the physically handicapped. If we look at the statics on clients served by Vocational Rehabilitation agency, the physically handicapped constitute the largest proportion though the mentally retarded and mentally ill constitute a far larger proportion of the handicapped population in general. It is one thing to supply a prosthesis for the arm that was lost by a previously intact organism, give a little counseling and a short period of vocational training to help him adjust to this newly acquired, circumscribed disability which he has and another to "rehabilitate" a retardate who has never functioned adequately.

Though we were unique in having vocational rehabilitation service made available to school-age clients through the contractual arrangement, when we examined the records we found that a surprisingly low proportion of all special class students ever received service through the Division of Vocational Rehabilitation. Even though the counselors went right into the schools and told the youngsters what might be available through this agency resource, adolescents are timid - they don't like to believe they have a handicap. It is easy for them to believe there is no problem because they are still protected by parents and teachers. It is hard for them to realize how much trouble they may have once they get out on the job. We reasoned that there must be some smoother way of promoting their use of this vocational rehabilitation source and some way of making it more a part of their lives, just as teachers and school counselors and so on are an integral part of their lives. We attempted to make this program an organic part of our program of special education so that at the point that they seemed to have gone as far as they could through the program of special education at the high school level they might receive preparation for work.

For this purpose, we build into one of the comprehensive high schools laboratories in which we could evaluate the work potential of the youngsters, not by the paper and pencil tests usually used in schools but by exploiting the work samples evaluation technology which had been developed in rehabilitation centers. We were most fortunate in venturing into this area in having sympathetic support from the rehabilitation agencies in the community. Before we wrote up the proposal we had opportunity to test the possibilities through a pilot study made possible by Opportunity Workshop. That agency provided us with the opportunity to enroll students at that facility on a half-day basis for evaluation and training while they continued in their school program the other half day. We tried out this method and we tried using work coordinators in the manner of the school work program for "normal" students. Legal opinions regarding the matching of federal vocational rehabilitation funds with state special education financing have made it possible to expand staffing of vocational rehabilitation services to handicapped pupils in terminal phases of their school programs. This source of staff financing coupled with staffing provided by the school system constitutes the present School-Rehabilitation Program, which is the extension of Research and Demonstration Project 681. The program of service is no longer limited to the retarded as it was under the demonstration grant.

What we need at the present time is a more suitable facility; our physical space is not nearly big enough to accommodate the need and what it might be possible for us to do under this program. The program provides a flexible means of designing different kinds of approaches to evaluation and training to meet the different needs of different handicapped people.

We have begun to modify our curriculum in some ways as a result of the project to introduce more vocation-related learnings. We now have one later elementary level class which is learning to plan, shop for and cook its own lunches. Each day the youngsters plan and prepare their own meals. They go through the grocery ads in the paper, decide the menus for the week, what purchases they need to make and delegate someone to go and buy the supplies. This requires figuring out the amount of money needed to buy the groceries, the amount of change to be brought back, etc. Student teams prepare the noon lunches and serve them.

We feel that it is important that the work training center communicate to the youngster: "You are a worker now; it's time to put away childish things and behave as a responsible employee." The work training atmosphere must be one which is expectant.

There is time for questions.

Dr. Blodgett: I would like to have you say a little bit about some of the practical problems of running a special class program at the elementary class level. What do you do about transportation?

Dr. Deno: The state special education law provides for coverage of part of the transportation cost for these youngsters. We have special classes scattered in buildings all over the city in regular school buildings. If there is no class in the school district of the child's residence, we transport him to the nearest class. We use taxis. There are strong disadvantages and no saving in cost to using big school buses in a district such as ours. Buses hold 35-40 children. If we were to use buses for transportation, these children would be on the road for hours. Because the children are scattered, the bus would have to travel over a wide area to fill its load. We use cab service for all of the younger children needing transportation. We contract with the cab companies. Cabs happen to be good unit size. A cab can carry eight children if the drop seats are used, and this usually is a very convenient size load. It may look very luxurious to take children to special classes by cab, but you can be sure that the school system had analyzed these costs over and over again and found it more economical or it wouldn't be using this method. The reason it is most economical is that if you have a bus and you employ a driver, you have to do something with the driver in the interim period during the day. Even if there is a regular job for him to perform, he loses time going from where he dropped the last child to where he is going to work. Only younger elementary children are cabbed. When children

get to be ten or eleven years of age, we expect them to take public transportation. This policy is followed not only because it is more economical, but because we think it is important that the retarded learn to be mobile, to know how to get around their city. We see this as an important learning experience that frees the student and increases his self-sufficiency.

Question: How does Vocational High School training program differ from Project 681?

Dr. Deno: Evaluation of the Vocational High School program was one of the objectives of Project 681. The program was instituted in 1946. At the Vocational High School, special class students are with special class teachers for half of the day in the regular trade training courses for the other half of the day. They are usually enrolled in such trades as upholstery, shoe repair, food service, welding, power machine, and other less demanding trades. What has happened to programs at Vocational High School is a good indication of how much more demanding all skilled jobs are becoming. It is rapidly moving in the direction of becoming a post-high school technical institute. This means retarded students fit into the trade classes less and less well. The Vocational High School program gives minimum help with social adjustment factors. There are always 400-500 normal students turned down at Vocational High School each year. Under such conditions, selection criteria can include behavior stability, responsibility, dependability, and so forth.

We have found that the kinds of jobs the retarded can perform don't really require a three-year trade training course to teach them. We can give that level of training in a shorter period of time and include personal-social adjustment training as a part of the training package. When reasons for losing jobs are analyzed, it is apparent that social adjustment skills are more important than specific skill training.

Question: What about the ages of the people at 681?

Dr. Deno: We try to design our basic special education program in the comprehensive high schools so it will be profitable for the student until the age of eighteen or so. A sixteen-year-old retardate isn't any more employable than a sixteen-year-old normal student. Theoretically, a pupil could be referred to the Center at the age of sixteen, but we don't encourage this. We take them only if they appear to be heading for drop-out. The age range is sixteen to twenty-one. We take youngsters who have completed a high school program also. They may even have gotten a regular diploma or a special education diploma. They can still come into the project for training.

Question: How long are they there?

Dr. Deno: As long as they seem to need to be up to a maximum of

two years. We are able to keep very few that long because we don't have enough staff and space to do go.

Question: What's the average length of time for a student?

Dr. Deno: At 681?

Answer: Mr. Krantz: The minimum is three weeks. It takes us at least three weeks to find out what we have on our hands. If they need service, some will be there for several months while they are making the transition. A student may be on a part-time job placement and part-time in the project for several months before he goes on full employment.

Dr. Deno: The student would be carried on the rolls of the project while on full-time employment and supervised by the project placement specialists.

Question: Are they always employed, though?

Answer: No, we can't bring everyone to a competitive employment level.

Question: How about some people that go through your program and go out and do another job - if they lose it, do they ever come back?

Dr. Deno: They are supposed to, and many have.

Question: They are supposed to? Then what do you do?

Dr. Deno: We try to figure out why they lost the job. Retrain them and help them get another job.

Question: Occasionally, from job failures you learn something else about what this person needs to learn?

Dr. Deno: This is why we think it's important to build up a familiar reference point for the pupil to turn to. It's much easier for these people to report back to Joe, to Ken, to Dick, etc. whom they knew before than it is to brave the formidable threat of an unknown agency.

Question: How much contact is there with the home to get them cooperating with the school program?

Dr. Deno: The Minneapolis Schools employ school social workers. We call them visiting teachers or special service teachers. They are supposed to do family counseling and provide liason with other agencies. They are so vastly overworked that they are not able to meet the need. When a student transfers to the School Rehabilitation Program (formerly Project 681) there is one person there who works with the parents and

goes into the home. He doesn't depend upon the parents coming to him. He familiarizes the parent with what the program is about, indicating the advantages there would be to the program. This seems to be very, very helpful. It works well.

Question: In the elementary classes, do you have a limitation as to the number of youngsters?

Dr. Deno: We serve fifteen, but again this is an issue of realistic functioning. We must have a limit or people would just keep urging us to put in more and more children. We have many classes that run with less than fifteen because the combination of problems is such that if any more children were put in the class, we wouldn't have any teacher to teach them. She couldn't survive.

EDUCATIONAL ASPECTS OF MENTAL RETARDATION

Mrs. Grace Warfield
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First of all, I would like to throw away the word "curriculum" because it is kind of tainted with pedagogy. I'd like to call it something else, but I'm not quite sure what. There could be "programs" or "plans" or "daily living" or a whole lot of other words. "Curriculum" connotes a planned program of learnings that children are expected to absorb during their time in school and this is not the way we approach our classes in the special education of the mentally handicapped. You will find hundred⁰ of curriculum guides that are written for states, for major cities; Minneapolis has some parts of one written. You can always get a good one from another state, if you should like to look at one. I brought along this small mimeographed brochure which we wrote last summer. Every teacher of elementary classes for mentally retarded has a copy, but I doubt she has looked at it because it is pretty fundamental or pretty elementary, my dear Watson. In the back of the book there is a large folded-up chart and if you have a little time, you might like to look at some parts of that. This chart couldn't fit on to a page, so we just spliced the pages together. It is a program guide for a child from kindergarten through high school in a class for mentally handicapped, regardless of his level of ability. It is divided into four areas: Preacademic, academic, prevocational and vocational. That's just another category of headings, which seem to us more appropriate for curriculum guides than grade or age levels. A child may remain in the preacademic category all the way along, especially if he is in classes for trainable children - yet he may get some prevocational training when he is older. The programing depends upon chronological age and the child's level of ability.

The vertical headings on this chart show the stress of emphasis: the first area is called basic tool learnings - language, art, speech, arithmetic, science, and so on. This would encompass most of the subject matter in regular classes through high school, but it's a small part of the program for the retarded. They need to learn other things in order to survive. The second area is economic competence - work orientation skills beginning with formation of attitudes and habits in early years. Next, we have competence for group living. Personal competence is needed in such things as health, habits, grooming, family living, money management problems later on, including personal adjustment to his own handicap. The next area is physical development, paying attention to health and safety habits. And the last area is avocational, self-directional or self-expression - that is, if you are retarded what can you do in your leisure time? Do you sit and twirl your thumbs or do you go out and play ball, or do some useful handicraft for fun? What do you do with all of the time you

have besides when someone else tells you what to do? I think this last area is one of the most important; I would put academic area skills down at the bottom. That's all I am going to say about this written material. I just thought you ought to know what we do in Minneapolis and this little pamphlet was written mostly for beginning teachers who are going out the first day and say, "What on earth do we do the first day in a classroom?" There's a little section for the "first day - primary level;" "second day - primary level;" "first day in upper elementary" and so on. Included are some pretests which will help a teacher to judge where a child might be placed in the program of learnings. If the child can't tell the difference between a circle and a square, the teacher knows she must start at a level before the circle and the square. If he can read and knows that a noun is a name, she had better start somewhere higher up. Rather than spending the time finding out, by talking to the child, or trying him out and having him fail, this kind of pretest in several areas may be a useful time-saver.

Language development receives good deal of stress. We feel that oral language, if developed fully, would be nearly all the "language arts" that a retarded child needs; a great deal of time is spent helping the child develop spoken language. I have a theory about why retarded children have so many problems in speech and why, even though they are able to speak clearly and articulate properly, they just don't do so. I suspect that when they began to talk, which was late, and their parents had begun to worry about them, that any sound at all that was recognizable as a symbol was rewarded so much by the parents that it became fixed as the child's language. There may have been little effort to correct his speech. The parents were so glad that he was talking at last, that it didn't matter that he wasn't saying things correctly. And by the time the child reaches school and we have speech clinicians, it's pretty much too late.

In spite of all of these curriculum guides, this is the thing I hear most often: "You know, that's a good one; it's got very good ideas in it." The teacher takes from a curriculum guide ideas, suggestions, and sources of material, but she has to develop it within the class on her own initiative. No guide can be written for any level that tells a teacher what to do, when to do it, for how long. It has to be varied according to her individual group. Guides for classes, as for science in high school, for instance, can specify a regular course to be taught and if the children get it, it's fine. And if they don't get it, it's sort of too bad, but the teacher doesn't have to worry particularly.

As we compare the programs for normal and retarded children up through high school, a wider divergence appears between the normal classroom and the special classroom. The young child, retarded or not, needs quite similar forms of experience; he needs activities for physical development and opportunity for oral communication. Later on in high school the program must be vastly different.

Teachers who are trained in regular classroom work often go into special classes because they feel they understand children, and would like to work with retarded children; sometimes they can make a good adjustment, but often they assume that their classroom with retarded children should look quite a bit like the regular classroom. They are most comfortable if the children are seated at their desks working when a visitor comes in or the principal passes by, because an orderly hard-working classroom is the conventional thing. It would not matter to the outsider, looking in on this classroom, whether the child was doing the very same thing fit the end of the year that he did on September 1st. It's possible, if he were a conforming child, to keep him doing the same thing over and over again for a pretty long time. But unless there is change and forward progress in what's being done, this is not a successful program.

Let us take a closer look at the programs at different age levels. In the primary age group, let's say ages four to about nine, the emphasis is in the daily life, the daily *classroom* life of the child; first, on physical development, large muscle, and fine motor skills; second, on language development - all communication with others in the classroom and with the teacher. Communication is not necessarily speech, although for some, this is the beginning of speech improvement which should be carried on continuously by the classroom teacher. We are working towards this plan in Minneapolis, but we still think that some retarded children could benefit from more intensive speech therapy. The third characteristic of the primary class for the retarded is that he has much opportunity to explore the environment, first within the classroom within the school, within the neighborhood; barriers of fear dissipate because A child learns to know what to expect of his own environment. If he is kept at his seat all day, he won't know what the ledge of the window feels like, and he needs to know. He needs to know the texture, the temperature, the purpose of many many parts of the world around him. He needs experience with objects, other people, animals, things of the earth, many field trips, many outdoor excursions, much freedom to interact with whatever happens to come into the environment. I remember one day in Roots 101 here. I had a very good program going and all of a sudden the children were distracted by noise outside the window. It was a kind of loud roar, and a couple of them ran to the window and wanted to know what that was that was going down into a hole on the side of the building. Coal was being unloaded into the old-fashioned coal bin. Now, the children had never seen coal and they didn't know what was going on. We went outdoors and got some pieces of coal so they could discover what it tastes like and how it marks up their fingers end faces. It's kind of getting outdated, you know; not very much of it is used, and the moment for teaching the children presented itself and if you don't take advantage of what comes over your horizon right then and there, the moment may be lost forever. Children here at the Sheltering Arms have a rich experience. All sorts of people come; for example, ambulance drivers have brought an ambulance - the children can crawl in and "go to bed" in the ambulance; maybe they won't be frightened

when they see their mother taken in an ambulance sometime. Policemen come, firemen come. It's not easy to take retarded children to all places, so if you have many visitors who bring parts of the world to them, it is to the children's advantage.

Fourthly, in the primary group, the development of fine muscle skills, finger skills, such as using a scissors is elementary. They learn how to use crayons, knives, forks, spoons and all kinds of instruments that children like to play with. Many of these items can be used in the classroom for learning. Two of the favorite skill-builders in the trainable classroom were the paper punch and the stapler. It was nothing to go through 5,000 staples a month. It was cheap and the child could learn how just the right amount of pressure on the stapler would do the job and when he could do the job, he had attained a email skill. Many of the activities in the primary room are built around the use of the fingers, the hands, the eyes, the ears, speech, voice; there is very little academic (so-called) work; perhaps there is experience in recognition of name, recognition of classmates' names, teachers' names, family names, recognition of familiar sounds, recognizing "exit," "stop," "go."

Not until the child gets beyond this developmental level does he get to the readiness or the academic work at the second level. This probably should not begin until about age eight. This varies greatly with individual children. Some six-year olds are ready to do some word recognition but it is relatively unimportant. Reading is terribly over-rated. Many people read very little. With radio, telephone, and television we can live practically without reading and many retarded individuals as adults earn their living with a minimal amount of reading skill. Yet our society insists that reading must be learned more quickly, earlier; now they can teach two-year olds. It is a highly respected asset and many times parents of retarded children say: "Why, he reads like a whiz - how can he be retarded?" He may read fourth and fifth grade level and still be one of the most seriously retarded as far as individual competence is concerned. So reading must be taken, not with a grain, but with a whole box of salt. It is important as a status symbol and the child who can read should be helped to learn

But it should not be given over-emphasis; it should not be given several hours a day when emphasis should be on other areas. In the upper elementary special class, reading usually takes over quite a bit of time. Children become interested in books and pictures. Value of numbers and symbols comes into use. In this age group, the maximum level of academic development is probably reached by the time the educable retarded child reaches 14; with trainable children it is probably younger.

At the next higher level, we now turn to the prevocational phase of educating retardates. There is more emphasis on group interaction, group projects, getting along with other people; interest is continued in personality development, habits, skills, learning to carry out responsibilities, becoming grown up, giving up the "baby" habits.

Showing affection is a normal trait that has continued to develop. There comes a time for change. A five-year-old rushing up to kiss a stranger was all right, but a 14-year-old looks pretty silly. Habits must be altered and this is done by reinforcing those habits that are socially acceptable. This begins not just now, but all along the way, to prepare to act like adults when they become adults. Reading is not put out of the picture, but it becomes more specific and purposeful, more associated with daily living and vocations.

The last step beyond age sixteen and upwards takes in the preparation for some economic self-sufficiency. This has been going on all along the way, but now comes the time, and the sooner the better. Is there any reinforcement better than money? A 14-year-old who makes 10c a day because he is dependable and can do a job and can depend on that money being his own, has a pretty strong reinforcement because this is what society gives him. Thus, we get to the area of training through our sheltered workshops and the school rehabilitation project which will be discussed more extensively by someone else.

Next, I want to talk about individual differences. Teachers of classes of the retarded must do a great deal more adaptation because the children cannot. They must be more flexible, more able to change to shift gears, because the children are less able to adjust. Otherwise, if the child could adapt, he could stay in the regular classroom. We have many retarded children in Minneapolis who are in the regular classrooms and are there by considered judgment. We think they are learning just about as much there as they would in a special class. They may not be so handicapped socially. They may have good home training, have friends in their peer group; they have good models to live with; in the classroom they see good social behavior from earlier years and they are as well off, if not better off in the regular classroom. Their academic learnings may suffer, but a skillful teacher can put this properly in place and the rest of the children in the classroom will benefit because they see and learn that there are some people who don't learn to read. This is something everyone ought to know.

Now for the children who must be placed in the special classroom in order to profit and have some of the individual differences which become the teachers' responsibility to manage. The first point is: they have very uneven skills. They may do fairly well with numbers but be completely unable to read, or vice versa. They may be able to talk a blue streak and keep your ear as long as you're bended; they speak quite well and can be quite socially acceptable, but they can't do a thing with their hands. And they are not very likely to earn their living by what they are saying to people. You teach them to be verbal. They need to be verbal and they need to have this development of language. One of the problems that a teacher has when a child has uneven skills is that she doesn't know what to emphasize. Should she let him be praised and make the most of the areas in which he is most successful or should she do some concentration on the areas where he is weak and try to level his skills? I think the latter - you need to

pay attention to all areas and do the best you can but be very careful not to over-praise a child just because he is a little more successful in one area. The other day I had occasion to see a child who writes poetry; because he is a bad actor and his poetry is reasonably good doggerel, he has been praised until the child thinks that he is going to be a famous poet. And he has already thought about getting a lawyer and getting a copyright on his poems. This was not a retarded child, but I just happened to think of the example. So you have to shut up the child who talks too much because he can't talk this way forever and you have to praise the tiniest bit of progress when he learns to cut a piece of paper an inch wide rather than a quarter of an inch. The parents will make the most of the child's strong points and! this is something you need to keep parents reasonable about. Just because he has a wonderful memory and remembers what happened when he was two isn't such a strong point. Kids don't have that much to remember and they don't earn their living by what they remember. In helping parents understand relative values of skills, the personality skills of being dependable, being likeable and trustworthy, are far more important than the ability to talk forever or to put pegs in holes forever. Thus, the teacher must carefully judge how to handle the uneven pattern of the child's skills in her programming and her counseling with the other people who deal with the child.

The second point in regard to individual differences is an uneven rate of progress. A child may have a spurt - seem to do very well, and then suddenly kind of wash out. You start children at the beginning of the year in a reading group. I recall having this experience; they were pretty much on a level and I thought this is fine - I've got so many in this group, so many in this group, and only two more - I can manage four groups, you know. But it wasn't very long before these four children were not together at all, and that one was obviously doing much better than the others. The worst problem here is to save face for the child who is obviously not doing so well. Believe me, they know. A teacher must constantly rearrange and adjust according to the rate of learning that a child is showing and find some way to reorganize and regroup without making it seem like a failure to the child.

The third point regarding individual differences is that the \ child is likely to have a good many other differences besides just poor mental ability. There are wide differences in his outside life, in his family experience; this is extremely important in the way he behaves in school or in a group away from home. There are wide variations in health history. We find it common that children have seen doctors a great deal, have been hospitalized, had many kinds of tests; their physical history and body functions are probably different; vision and hearing loss have been present. Logs in vision and hearing can be very important. If it is not picked up it will further accentuate the differences in this child.

There is a fourth area of individual differences which you can do

something about or teachers can do something about. (I am talking as if you were teachers and I realize you are not all in this profession.) The environment for a group of retarded children can be manipulated to some extent by the person in charge, if he knows why and what he is doing. For instance, a teacher may spot a child who is erroneously placed, even though he has had very good diagnosis. He might be able to profit from another kind of group. In spite of very good study and good administrative attempts, we once in awhile find some wrong placements. A teacher can manipulate the plan for a child and if it is not done while he is young, time may be lost. I had occasion to observe some trainable classes in which I noted two children about eleven years of age who were obviously gaining little or nothing from these classes. One of them had been there four years and the other three years and they were clearly below the level of the rest of the class and the teacher was unable to provide anything other than custodial care. The teacher needed to have someone to whom she could make a recommendation, such as a social worker or supervisor. These places were being taken by children who would have profited, I think, from institutional placement, and the places in the trainable class could have been better utilized by others. Another factor that can be changed is better grouping of children according to developmental age and abilities. If there is more than one class, regardless of where they happen to test, they may fit into one or the other groups better. There is an advantage in having a group of classes so that some of this management can be done. I feel really sorry for the teachers in rural areas where they have the age range from 6 to 21, sometimes even beyond that. This is not a true classroom setting, it's one kind of group experience. It may be other things, but it's not education for social development as adequately as when we are able to group the children by age and developmental need.

I vent to get on to the behavior difficulties because this is a fascinating subject and one on which I don't have very many answers, but I can raise an awful lot of good questions. It is probably the area in which teachers have the most difficulty and ask the most questions, and it is the areas in which we are asked to help more often than any other. The teacher of retarded children in a school may even be asked to advise on behavior problems of children in regular classes because she has some experience with unusual behavior. Many of the teachers who go into teaching emotionally disturbed children seem to have had some experience with retarded children. In our observation some of the best ones come from the training in teaching mentally retarded.

Behavior difficulties that give the most problems to teachers include: aggressiveness; attacking other children, or being self-punishing sometimes; attacking the teacher; destroying property; destructive tendencies, such as tearing up books, kicking out windows; doing things which are outside of bounds and are endangering the lives of one's self or others, like climbing stairways when there aren't any railings or roofs. This causes a great deal of concern to those who

are in control for the safety of the child. Impulsive behavior is which the child is uncontrollably acting out leaves you never knowing when to expect a blow on the side of the head. Impulsive behavior is one of the truly difficult characteristics. Then there is just pure negativism, "I'm not going to do it" or "I'm going to do what I want to and not what the teacher says." A short attention span means that no matter what activity you present or plan, the child is into it with fervor for a moment and then out of it, and you have to be quick to think of something else before he gets into something he shouldn't be doing-

There used to be a good deal of concern about children who were withdrawn and refused to speak, et cetera. Typically, they were easier to handle, that is, they didn't bring themselves to the attention of the teacher and it was thought that these were probably the most seriously disturbed children. Studies have shown that it is not so; there are fewer individuals who turn out as adults to have serious difficulties who were withdrawn in childhood. It is the aggressive and acting-out children who turn out to be the aggressive, delinquent adults. So there is some justification for thinking that when the teacher is concerned about these children, it is a serious problem. I'm going to make just a few suggestions about what I think helps in handling these children, and I speak partly from experience and partly from listening to other people who work with disturbed children.

I think it is most important to know normal children pretty well to be able to know what to expect from a child at a given age. Then, when you have a retarded child, you take the difference between his mental age and his chronological age into account and somehow you don't balance it exactly, but you know these two things are present. His behavior for his mental age may not be so strange, if you know what normal children of that mental age would be doing. Two-year-old children are not particularly conspicuous because they have a lot of tantrums, but twelve-year-olds are. You would know that it was a fairly serious symptom in the twelve-year-old. So a good deal of background in development of children and children's behavior is a great help.

The second point is to know the individual child thoroughly, as much as you can find out about him from all of the people who have ever worked with him; all of his medical record, history of experiences, hospitalization, special problems, and particularly his family life. If you know what his parents do with him after he gets home from school, when they are with him, what his brothers and sisters do with him, who he plays with, who respects him and takes time and shares with *him* - experiences in life, - all the knowledge you can gain. I think a home visit, especially if there is a disturbance, is one of the very good ways of finding out a great deal. This will give you kinds of insights I can't explain. It's just that in knowledge is power and the more you know, the more you feel you do have some ideas that you can begin to put together.

Having all of the knowledge that you can obtain, the next step is observation and not for just one day, but over a period of time. One of the things most important to consider in a child if his behavior is asocial: What is it that keeps that behavior going? What kind of a reward is he getting for pulling these tantrums? Is he doing it because this is the one way to be sure he gets attention and make sure that controls will be set for him? Is it more comfortable for him to have someone holding him back because then he knows he isn't going to hurt anything? It's possible. The whole system of reward and reinforcement of behavior in young children is a very fruitful field of inquiry. A second point regarding observation is to note the changeability. How much variation is there - is he always the same or are there periods when he has different kinds of behavior? You might look to both physical reasons and emotional reasons for difference in behavior. If he has a short attention span and he doesn't seem to be able to stay with anything, you might try lower levels of activities to see if he will stay with something longer. He may not want to put a puzzle together; maybe he can't, but he will play in the sand for an hour. Or he may not care about a book, but he will take puzzles and work with them until he is successful. If a child has one area in which he is showing some ability to sustain attention, there is some hope that maybe this is a matter of experience. When he is successful in other areas, he can extend his attention to other areas, but when there is nothing that will hold his attention and he stays two seconds with every single thing, I would suspect that you would need to look further for a physical reason. Maybe the child cannot profit from even the best situation; he may fall into a category of needing medication to slow him down temporarily, or he might need to be in a more restricted environment until some saturation takes place.

All kinds of things may cause negative behavior and there are all sorts of ways to see it and the first thing is not to be threatened by it. Just because the child is negative, the teacher doesn't have to be concerned about it. You can become negative, too. You can take it with a grain of salt, a sense of humor, and say, "You don't know what you are missing; so you don't want to do this but the rest of us will anyway." You don't have to force every negative child into every activity. He may learn something from being negative and maybe it isn't negativism. Maybe he is scared and he wants to watch for while. After he watches other children, he may join in. Sometimes a habit has held over from patterns of childhood where this negative behavior got rewards. In order to live at home he is negative because then his mother knows what he wants - he needs to be fed or he needs to be put to bed. She may understand his negative behavior. I would suggest that problems in behavior need to be discussed with parents to see if the child behaves differently in school than he does at home. There may be some clues here as to reasons for the problem.

Now, I want to talk a little bit about some techniques in the classroom. The structure of the classroom, which is handled by the teachers, is of paramount importance in controlling children who are inclined to have difficult behaviors. Who sits in the front row and

who sits in the back row may be terribly important. And how far is the distance between Johnny and Peggy? Can they reach each other by a handshake or will they bump into each other? Classrooms sometimes are just not large enough to allow the amount of distance that is desirable and necessary. I think a classroom for the retarded needs to be approximately twice the size - that is, we have fifteen children in a classroom designed for thirty. That is the minimal amount of space. There really needs to be more than that and a whole lot of storage space besides. But the teacher in structuring the group, knows that the place the teacher is at all times may be extremely important to the group. Whether she's behind them or in front of them may make a difference. If she stands between two children or with one hand on Johnny and one hand on Mary, she can manage the group, but what if she's got Peggy back here and needs another hand and she has only two? Teachers need more hands. The physical presence of the teacher, the touch of the teacher is important especially to young children. One child may need only a pat or a touch but he needs to know what will happen when he gets too far out of line.

The activity level in the classroom is also of great importance. This varies from teacher to teacher and from group to group. But the children must be busy. Maybe they are busy waiting, but they must be busy. They must know there is a reason for doing what they are doing. Maybe they have something to look forward to if they are waiting, but once a child gets bored he is pretty apt to stray. We have some interesting reports about some studies which were made about kinds of classroom structure* and structures in group work with children. These were emotionally disturbed children. There was a study made of a summer camp, where a counselor and a group of five children in different situations were observed. There were art classes, bathing, swimming, cookouts - all of the activities that go on in summer camp. The most successful activity for the children having behavior problems was swimming, perhaps because the water itself exerted some sort of control - they couldn't move quite as rapidly in the water. Every child was busy and there was plenty of room for everybody. The least successful activity was the cookout because here there was a group of children smelling food; maybe they were hungry already, and there was the danger of fire and a certain number of warnings had to be given and not all of them could get their wieners roasted at the same time. So you have a lot of rivalry and impatience based in part on the physical factors of the whole setting. Some of us know that the hour before mealtime is probably one of the most difficult ones in the classrooms for retarded children. Now another part of this study concerned the disturbed children within the classroom itself. Three kinds of activities were observed. There was an arithmetic lesson which was sort of a programmed activity in which small units were set up, one after another. There was a social studies group in which children were divided into small groups, planning for a report. And there was a gym period in which the children were lined up waiting for their turn to practice throwing the ball in the basket. Now which one of these would you say, with all of your knowledge to date, would

be the most comfortable or have the least behavior problem? The gym? No, in the gym period they were lined up waiting to throw the ball and they were too close; they were pushing the ones in front and kicking the ones behind. In the social studies group they were arguing about what they were going to do and they didn't have adequate leadership. This resulted in a whole lot of quarreling and bickering. The best program was the programmed math, where the child had a small task, saw immediate results, knew when he was right and could move on to the next set of problems. Each child was busy, not being distracted by his neighbor as in both the social studies and gym period - he had his own successful activity. This is one form of classroom structure that cuts out some behavior problems.

Of course, one of the things that we are wanting most of all is for these youngsters to get along socially with each other, and if we set up our whole program so there wouldn't be any behavior problems, they wouldn't learn how to behave, because it would be always controlled for them. So the kinds of interacting activities in which they can get along the best need to be studied. With many groups, dramatic play is a very favorite form of activity. There is nothing like acting in another role to make one feel important. The number of boys who want to be doctors in dramatic play is phenomenal and the girls will do well as teachers or bosses and you will see them be mothers and fathers and acting in some ways better than they do as children. They reveal some things too. One of the best activities with a group of disturbed children, if their interest is caught, is dramatic play, because this has a small proportion of audience, of people looking on; everybody is busy doing something which makes him feel good or important and he is trying on a role of good behavior. Of course, you sometimes have to let him be the bad men in order to act it out. This may be good for him, too. It's legitimate then to shoot and cuss a little and go on. Another area which provides for acting out some of these behavior problems is that of games or action in response to music. Here the child can bang some of the instruments, make his feet loud on the floor as he is never allowed to if he is just walking. Giving the children chances for an expression of feeling through physical activity allows for some satisfactions. Another medium which offers a healthy outlet for feeling is clay. Young children can do all sorts of things to clay that they would like to do to people. They can gouge it and pound it and push it and step on it and chew it too.

The kind of authority or the focus of authority in the classroom is extremely important in the handling of behavior problems. I have observed a good many teachers and every one has a style of her own; there isn't any one kind of classroom that is best. Sometimes children seem to be better in a permissive sort of classroom and other times they can operate only in a very structured classroom. But these can become too extreme in either direction. The authority is set by the teacher and the group itself -- the teacher interacting with the group. The best kind is that which is not seen or heard. All it takes is a small movement of the teacher or a look; if she turns her head towards a child over here the child over there knows that she is going to turn

there next. He knows what he should be doing and so he is doing it when she does look that way. The less said by the teacher, usually, the better. Eventually as she handles it more and more by nonverbal controls, the more democratic the classroom can become, because then authority becomes a personal sort of relationship with each child and it doesn't have to become conspicuous to the whole group. The group itself, in a democratic kind of classroom will take over some of these controls. This is often successful when there is only one child out of line. Get about three of them and they constitute a minority and they can sometimes make it uncomfortable for the rest of the class. It's very easy to over-balance the load in placing these youngsters. It is easy to overbalance the classroom so that a teacher who has had a comparatively calm classroom, by the addition of one more child suddenly has an explosion. Sometimes the interaction between a number of difficult children can become puzzling for a period of time, but good teachers can usually work this out. I have observed that teachers would rather, in many cases, start with their entire group in the fall, than have children added gradually. This surprised me at first but as I thought about it, I perceive that once the structure is established in the classroom, the addition of one more child can be upsetting to a teacher who has it already well organized. Several times I have made an assignment of a child without any known particular problem. The teacher calls up the first day that the child is there. She absolutely can't stand it, she just doesn't know what to do, and she can't have this child in her class. Rarely can an immediate change be made but we promise to look at the situation and do what we can; if she can't keep him we will find another place. By the time a week goes by I usually get a call from the teacher, "Well, he's really doing much better. The last three or four days things are fine." Now, it is a little different when you have a situation like Sheltering Arms, where there are other people around who can take off the drain of one additional person, if it should be too difficult when he is first placed.

I want to say a last word about the teacher. The most important part of the curriculum guide is the teacher herself, her whole personality, outlook and mental health. I think it is not nearly as important what the children are learning, as the way they feel about what they are learning. It is fortunate indeed that the teachers have as much latitude as they do and they don't have a too structured curriculum. They can do some of the things that they like to do best, communicate to the child that this is fun to do, this is worth doing, and worthwhile because we can do it. The teacher has a lot of choice, and this is necessary and good. The successful teachers work this out in their relationships with each child. When you have a separate relationship with each child in the group, it's sort of like a huge team of horses - the teacher is here and somebody is way out there, but she has all the reins and a finger on the line that leads to each one of the children and, no matter what his behavior is, she has a little bit of control over the child. There are children who come outside of every teacher's credibility and possibility and I speak from experience. There are some children that can't tolerate the school setting, and a teacher is a human being. Here we need a good

administrator, so that the teacher can say: "Honestly, I can't stand it and would you rather have me or the child?" Some kind of change can be made and somebody somewhere else can do more for this child because there is a different program, with a different kind of structure, which will meet this child's needs.

Where did I leave out sense of humor? You have to be able to laugh with the children and have fun; if you don't enjoy them, and can't help parents enjoy them, you shouldn't be trying to work with the retarded children.

PARENT EDUCATION AND COUNSELING

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Today we are going to talk about parent education and counseling. In general, we believe that parents carry responsibility for their children and this is where we start when we begin thinking about educating and counseling parents. For our framework, at least, I would differentiate a little between parent education and parent counseling. I would consider parent education to be more of a group approach, while parent counseling is more of an individualized process. That is the way I'll be using these terms. Since parents, in our society, do have this responsibility for their children, we make a basic assumption that it is good for them to know as much as they can about their child, to understand him as well as possible. We make a further assumption that parents, in general, have good intentions. This assumption is not always true. There are parents who do not have good intentions. There are parents who, although their intentions are good, have nothing with which to implement their intentions. There are parents who think their intentions are good, but we might not agree. Still, the general assumption we are making is that most parents will want to "do right" by their child. There are some very basic differences between the way parents can look at their child and the way professional workers can look at the same child. One of these is a difference in perspective. Although the parent sees the child as he is, right now, with problems which at the moment are important, he also has a total longitudinal picture of the child. He remembers when he was six hours old, and six days old, and six weeks old and he carries this longitudinal view of the youngster along with him, even though he also has the cross-sectional view of what is going on right now. The professional person usually has not had this longitudinal view at all. He sees the child at the point that the child gets to him. This is what he bases his judgments on and what he bases his plans and recommendations on. These two kinds of perspective may be rather different.

It is also true that, by and large, parents will be more emotionally involved with and identified with their child. This does not mean that professionals may not also be emotionally involved. I think that any teacher who has worked with a group of children would certainly agree that the professional, too, comes to be involved with the children with whom she is working. It is, though, a different kind of involvement than the parent has, and probably a lesser degree of identification. A teacher can be "involved with" without being "identified with."

The parent also has another difference from the professional. The parent has to be concerned with the whole family situation, of which this particular child is just one part - maybe the most troublesome part, or maybe the least troublesome part. At any rate, the

professional concern is likely to be directed at the child as an individual person, while the parent has a million and one concerns about the other children in the family and many other problems of living.

There is one further major difference between the view of the parent and that of the professional, and that is the difference between what the professional knows about child development and what the typical parent knows. The typical parent probably doesn't know very much about the nature of the childhood growth and developmental processes. The typical parent learns this as he goes along, insofar as it applies to his own child. He learns from his own child's behavior and development something of how behavior and development progress, but the professional has learned this on a much broader scale. He has a much more extensive fund of information. He knows, for example, that negativism is quite common in children between the ages of two and three, and he knows that negativism in retarded children is generally a much harder thing to help the child outgrow than it is with normal children. Parents often have quite fixed ideas which are just plain wrong from the viewpoint of scientific knowledge about children, and it can be rather dangerous to say to the parent flatly "You're wrong about that." There are times, though, if you can't say this to a parent, firmly if not flatly, you aren't going to be able to make much further progress, because if they are convinced about this false concept, whatever it may be, then you aren't going to be able to sell them the kind of information you want them to have and to use.

Of course we have talked about communication problems and skills all through these trainee sessions, and there are several questions about communication. We might say first, what do we need to communicate? What is the content of what we want to say? The answer to this depends on who it is doing the communicating. Let's consider the psychologist, first. Usually the psychologist has some quite specific kinds of information derived from measurement. These are not whimsical sorts of things, not things the psychologist invents in his own head - they are based on what the child did in a standardized situation under standardized conditions. They are measurements of some kind - ability, or perhaps achievement, perhaps with older children some personality measures. More often with young retarded children the psychologist won't have personality measures to interpret, but he may have some important personality observations, because as the child is operating in the setting of the psychological evaluation, he is being looked at. The psychologist is making mental notes of his degree of cooperation, his level of motivation, his sustaining of interest, his handedness, his recklessness, his attention span, his degree of hostility or how much he hates the world around him - all these things are being noted. If the psychologist has a chance to see the child in a free situation, such as a playroom, he can pick up other kinds of observations - about his interests, the things that he stays with for a long time, the things he loses interest in quickly, his dependence on the adult.

Very often, as a result of the measurements and observations, the psychologist will have some recommendations to make to parents for things they could be doing differently, and some suggestions for desirable outcomes toward which the child could be moving.

If the person doing the communicating is a teacher or someone in a teacher role, there are other kinds of information that he will have to communicate. Certainly of primary importance is information about how the child adapts in a group. This is something the parent may not have had a chance to see, except insofar as the family situation provides a group. Parents are very often not well aware of what their children are like when they are with others of their own age group. The teacher is in a position to describe the child as a learner - what he is learning, how he is learning it, how interested he is in learning it. The teacher will also probably be in a good position to talk about adjustment problems in the classroom - where does this child run into trouble? What kinds of conflicts and collisions does he have with other children? Is he one who is easily stimulated into a kind of behavior which, left to his own devices, he usually doesn't show? Is he one who is quick to imitate what other kids do? Is he one of whom the others are imitative? Is he one who sets the pace in the classroom? Is he one who can be relied on to take any kind of responsibility? If so, what kind? These are some of the things about which the teacher is the expert informer.

The social worker may many times be in a position of representing the viewpoint of either the teacher or the psychologist, and this puts a special burden on the social worker, because, as you recall from Mr. Olson's lecture, the longer the chain of command, the easier it is for misinformation to be transmitted and for communication to break down. If the social worker is the one who carries information from the teacher or the psychologist to the parent, the burden is especially heavy on her to make sure that her interpretations are correct, that she is faithfully carrying out the intent of the teacher or the psychologist in what she is reporting. The social worker is often in the best position of this team of people to interpret within the framework of the family, because she is apt to be the one who knows most about what the home is like and can translate information into terms that will be meaningful in that home. The same interpretation might not be meaningful in an office setting, because one might just miss the level of communication complexity that these parents could tolerate or could take.

All of these people are involved in communicating; all of them may be involved in planning; all of them may be involved in specific advice-giving, and I'll have more to say about that later. Certainly, all of them will be involved many times in saying things that are hard to say to people. I think this is something to which people new to the field need to give particular thought. If we are going to invest ourselves in communication, and some of this is going to be information that parents do not want to hear, we have to stiffen our backbone

enough to be able to Bay it in ways which are as little upsetting as possible, but still, ways which will let the truth get through. I think a very serious mistake that many people in all the professional areas - teacher, social worker, psychologist - have made many times is to "water down" what is the truth to the point that the parent doesn't hear what is the truth. It really isn't the parent's fault if the teacher or psychologist or social worker has said something which has ,a negative connotation in such a gentle way that it turns out sounding like a compliment - we can't be surprised if the parent doesn't hear the message. It has just been lost in being diluted. We have to pay special attention to the clarity and precision with which we speak.

If this communication is so hard to do, why do we bother? What is the point of this communication effort? There are several reasons why we bother. Certainly one, and a very frequent one, is that we want the parents to do something for the child or about the child. Perhaps we want them to do something different from what they have been doing. We may want them to change their attitudes toward special class. We may want them to change their attitudes toward retarded children. We may want them to change their standards of what they expect from this child. We may want them to de-emphasize discipline in certain areas and perhaps emphasize it more in other areas. In other words, there is a selling-aspect to interpreting facts about retarded children in terms of what we want the parents to know, or think, or feel, so that our work will in turn be facilitated. I don't think there is anything especially wrong in seeing this as a sales approach. In a sense, we want to present information in such a way that parents can "buy" it - accept it, hear it, believe it, incorporate it into their own thinking. It's important too that we communicate because the child is the same child at home as he is at school. He does not live in a fractionated way. He brings himself with him; he brings his experiences with him. When he goes home again, he takes the school part of him along with the home part of him - he's the same person. Another reason for communicating is that; in general, parents want to learn. They want to do a better job; they want to upgrade their own parent behavior. We can document this, I think, by attendance at parent meetings here at Sheltering Arms, by the kind of attendance they get at the Mothers' Club at the Minneapolis Association which is run for parents to whom the diagnosis of retardation is new. People will make some effort to learn if we will make the effort to help them learn.

Many of you will be involved in interpreting test results, partly because so many people are scared of psychologists. The teacher, the social worker, the activity center leader may be a less threatening person to parents than the psychologist who many times carries the magic title of "doctor." Many parents will hesitate to approach the psychologist with questions that are very important to them, but they will not hesitate to ask the child's teacher when they get to know her. Consequently, many times teachers are in a position to help parents understand intelligence test results and what they mean, even though the parents have already heard the same information from the psycholo-

gist. There are some tricks of the trade that you can use to help translate some of the information into meanings for parents. One is to do it in multiple ways. Don't talk just about IQ scores; don't talk just about mental ages. One of the problems of using the mental age comparison is that it doesn't stay put. A child is tested at age six; he gets a mental age of three. The parent gets the idea that he is three years "behind." They take this information with them. Six years later the child is twelve, and the parents are still going around saying he's three years "behind." Of course he isn't. He is about six years "behind," because the important thing that they should have understood when he was six years old was the concept of rate of development, and this they missed. So they are thinking in terms of how many years below his age level he is, when what they should have been thinking about is his rate of mental growth. Whenever you are interpreting IQ scores to parents, a very good thing to do is to stress this rate of development aspect. Suppose test scores are in the borderline range; this means generally that he is developing at about three-fourths of the normal rate. You can apply this at any age (assuming re-tests from time to time to check on the rate of development), and it will help the parents keep pace with the child's amount of retardation at different ages. I think that using a mental growth chart with parents to project the child's mental growth to future ages can be very useful - you remember you saw the chart I use earlier in the training program; this helps parents see the increase in the gap between normal and retarded as age advances. To begin with, a retarded child can't be that far below his age level because he hasn't lived that long, but as he grows older, the gap widens. This is something parents need to appreciate and it is more easily visible if you can put it on a chart. I think it is usually helpful to talk in terms of a range of scores or a zone of ability rather than in terms of single IQ points or scores. For this reason, I think it is always desirable, although it isn't always possible, to have more than one kind of test administered to a child. We make a point of using performance as well as verbal tests and supplementary tests, so that when we describe a child in terms of his test performance to his parents, we can say, for example, "Well, this particular boy does a lot better with handling things than he does with handling words and ideas" - if his performance test score is 80 and his Stanford Binet score is 60. This is important for parents to know because it has a bearing on what they do with him at home. Are they going to "lead to strength" and focus on the things he is good at, or "lead to weakness" and focus on things he is not able to do? The test scores don't answer this question, but they do help in describing the child more completely. If you know about the differences in ability patterning the child shows, you can give people a little more specific guidance about their own child. At first, parents tend to think in terms of a fixed IQ and this is a limited kind of thinking. What you want parents to come to appreciate is the general ability level. We focus on this somewhat when we talk about educable and trainable levels. Sometimes we have to make a further explanation to parents when we find that a child, perhaps around the age of eleven, with an IQ of 56, cannot function profitably in an educable classroom.

Then we have to say, "Yes, educable in test score, but not in actuality, not when applied to the real test of life performance. Then we have to try to explain that the test score does not correlate perfectly with what the child can learn. Specific disabilities can enter in and interfere with his use of his general ability level, so that a severely perceptually damaged child, IQ 56, probably will fit in better in a trainable situation at this age because he won't be able to learn to read by any techniques that we now know how to apply.

We also want to tell parents about qualitative aspects of test performance - not only what level of difficulty of task he can do, but how well, qualitatively, he can do it. What is his interest span? Will he stay for a long time with something he likes and give up immediately on something he thinks he can't do? How easily defeated is he? How much frustration can he tolerate without falling apart? If he does have a tantrum and blows up, how does he get reorganized? These are behavior things, not as precise as IQ scores, but things which have very much interest and significance to parents.

Another thing you do in interpreting test results to parents is to scotch the opposition before it gets started by recognizing the limits of tests. This is perhaps one of the most basic things to do. Many parents come to a testing session with their child with a built-in, very deep, fear, hostility, and resentment of this magical device that is going to label their child. Well, of course, it is not the test that labels the child at all - he has already been labelled with some kind of label or they wouldn't have bothered to bring him. But this - the testing session - provides the confirmation of the label, or gives a more precise label, and parents very often hate every second of it. They want it and they don't want it. They want to know and they can't stand it to know. They would rather you would tell them anything else about the child - he is schizophrenic, he is totally deaf - they would rather hear almost anything than retardation. This is changing some, but there's a long way to go before it is totally changed, and it is a real problem. Parents are going to take out their resentment of the whole situation on the test. Often a parent will report, "He was tested at school, but they only had him there for about ten minutes, and what can you find out in ten minutes?" Well, if you are the school psychologist and the only kit you have with you is the Stanford Binet, and this child can't talk, you can find out quite a lot in ten minutes. You can find out that you can't test him adequately with the instrument you have at hand, for one thing. You can probably make quite an accurate estimate of his general ability level through observation and partial testing, but the parents don't always know that, I personally think it is perfectly legitimate to keep the child in the testing room for longer than is needed for the actual testing, for a number of reasons. One is that it does give the parents an increased confidence in the kind and amount of effort the psychologist makes. A ten minute session would not be very reassuring to an anxious parent, but an hour's session looks a little different, and certainly the psychologist is learning something; he isn't just

taking a nap and waiting for time to pass. You can say to parents, before they say it to you, "Of course tests don't tell us everything about children." If the psychologist says something like this, non-defensively, before the parents can become accusatory, he has taken away one of the defenses which needs to be taken away in order for the parents to listen to what else he has to say.

It is useful, too, to relate the use of the test to the reason for the study in making your interpretation. How this is done depends partly on the sources of your clientele. For the past ten years, most of the children I have seen have been voluntary parent referrals - the parents themselves sought the study. Of course, many times some one else may have suggested the need for the study, but the parents took the initiative in making the appointments. This is very different from what is the usual public school situation in which the teacher first sees the need for the study, the social worker talks to the parents and gets permission for the study to be done, and the psychologist goes to the school and sees the child. This is, in a way, a more "second hand" kind of procedure. Many times, even though the parents consent, they do so without really understanding what the problem is and they may have the feeling that they are giving consent under some pressure, although actually this may not be the case. If parents have sought study because they want to make some special school plans for the child, this is a logical place to pick up the interpretation. If they have sought testing because they are concerned about the child's behavior, then this is a good place to begin interacting with them. If they have sought it because somebody told them to - perhaps their doctor - then this is a good place to start, with a question such as, "Why did your doctor suggest that you bring Ricky over here?" Immediately they have something to tell you, and this facilitates their listening when it is your turn to tell them something. Certainly it is important to talk in terms that parents can understand. How are you going to know this? Well, you don't always know at the beginning. One good way to find out is to ask them to tell you something about the child before you start interpreting the test, and by noticing the kinds of things they tell you and how they express them, pretty soon you have a notion of what they are ready and able to listen to and understand. Many times parents of retarded children find it possible to work into their own conversation something that gives you clues as to their educational level or their training or the specific reasons they know something about retardation. If a mother says in the first few minutes of a conference, "Well, of course I have been worried about him for a long time because I was a nurse before I was married and I could see for myself that he wasn't developing normally." Okay, you have your level established. You can now treat this more on a professional level as far as vocabulary is concerned, with regard for the mother's knowledge and experience, and you can move along faster and better than if she hadn't told you this. Another mother might say, "Well, I don't really know much about children; I never had a chance to go to college. I have done some reading about brain damage, trying to understand Ricky, because the doctor

said he might be brain damaged, but I can't really make much sense out of it." Then you know that you need to start at a different level, with less professional vocabulary and probably a slower pace. Suppose you make a mistake, which can happen. I talked with a father not too long ago and sized him up as a professional-level person; it later developed that he had had a terrible time in school and hadn't finished high school, but he talked in a very polished, well educated way with an excellent vocabulary. Much of his education is self-education, but it's still there - so it isn't just the educational level you need to be alert to, it is really the comprehension level you are looking for. You can check on things as you go along. Stay alert to note how people are listening. If you use a big word or a technical term, follow it up with a definition, an explanation, or maybe an example. Sometimes there just isn't a single word that expresses what you want to say, so you need to use the professional word. For example, perhaps you are talking about autism. There isn't any layman term that means autism except autism, so you use it - but, if you are not sure the parents are understanding, you supplement the word by adding something like, "That's a word we use to describe a child who doesn't seem to form relationships with other people and seems to live in his own world."

Another thing which is important in setting and maintaining a good climate for communication is to avoid any kind of blame. Parents often have done something wrong, made mistakes. Parents are not paragons of every virtue any more than the rest of us are, but it¹ is only looking backwards to focus on this part of it. Here is a child, age six, who has a terrible eating problem. You know very well that if the parents had done some things differently, the chances are about 90 out of 100 that the eating problem wouldn't exist, but there is little point in digging up the dead and buried past. Let it lie there and think in terms of where do we go from here. Instead of saying, "You shouldn't have let him dictate all the menus since he learned to talk; this is where your problem came from," you would say, "Let's see what we can do now to modify his eating habits," You move immediately to a constructive plan of action. The point of this communication is for the future, not for the past. Another example is that of the physically handicapped child. I don't think it helps much to tell parents of a crippled child that they have overprotected him. This is about 100% true, but it doesn't take you anywhere. If you can get the parents to tell you that they have been overprotective, it's a little more useful because then they are getting something out into the open where you can help deal with it. If you say, in effect, "Of course you have overprotected him and it's all your fault," this isn't going to do much good. You can discuss the fact that he has been overprotected without implying that parents are to be blamed for this. You can say, "It's almost inevitable that a physically handicapped child does get overprotected at home," This isn't saying, "You have overprotected him." It is rather saying that this is something that has happened - he did get overprotected. Just by changing the verb form, you have saved something of the parents' self-respect.

Another point in talking with parents concerns willingness to make specific suggestions. Many parents want you to tell them precisely what to do so they can go home and do it, and when it doesn't work, they can say, "See, I knew it all the time." This is a good reason for not giving just one suggestion. In fact, if you can't think of more than one, I would suggest often not giving any. I think you want to give the parents some things from which to choose. This is their job; this is their responsibility. This is, after all, their child. So you don't say, "The only way to handle an eating problem is to put his food in front of him, leave him there twenty minutes, and then take the food away. When he's hungry, he'll eat." This may not be the way these particular parents can behave. You can say something like this: "Some parents find that the standard advice works fine, when they get around to trying it. For most children, if the food is there and they are hungry, it's true, they'll eat. But not all parents can do this without becoming too anxious or upset, and you happen to be one of those, then it's probably better to take a little different approach. Why don't you try withholding his dessert if he hasn't eaten his dinner?" You can find other ways of coping with the problem which avoid the formula fallacy, because actually I know of no formula for changing children's behavior. Different things work when tried by different people in different atmospheres and in different constellations of family influence, with different children. Even the things that may seem to you very obvious may not seem obvious to the parents. I think it is a good idea to offer suggestions, not as a panacea, but as possibilities. So you might say, "Had you thought of trying this?" I like to think of these suggestions as a cafeteria situation - you set out the suggestions in little dishes and the parents walk by and pick up the ones that appeal to them. They make their choices in terms of their own personalities, in terms of their family situation, in terms of the relationship that exists between the parents. Of course, it is easier to offer suggestions the longer you have been working in the field, but it isn't necessarily any easier to offer, them with confidence because the longer you live, the more you know that the panacea thing just does not exist. I think there comes to be an increasing humility in professional people as they work with parents and try to give them suggestions that might be helpful. Sometimes it is easier for parents to accept suggestions when they come from other parents, even though it is the professional person who is making them. You can say, "Some other parents have told me how they handled this kind of problem, and it worked well for them." It is important, of course, to try to fit the suggestions to where the realities of life are for the parents. I think of the story about the doctor who recommended for his nervous patient that she take a six months' ocean cruise, when what she was nervous about was that the unemployment insurance had just run out. There isn't much sense in recommending that a family send a child to a private school if they are living in marginal circumstances. You have to be realistic about what is going to be possible, although this doesn't mean that you can't discuss these other things. You might say, "Well, this type of private school would be fine for Jerry, but I don't believe that's going to be possible

in your situation, so let's see what other things we can think of that might be possible."

It is also important in talking with parents to make use of some little things as well as the big ones. I think this is especially important for teachers, who have occasion to notice many things about their youngsters. Even among the most difficult children, there are some likeable traits and some things which can be shared and enjoyed by both parents and professional persons in a conference. Many parents, we need to remember, are basically quite ambivalent themselves as to how they feel about their child. They aren't too sure they like him, and with reason; much of the time he may not be very likeable. Yet, for them to be able to carry the load of responsibility they have, it is pretty important that they try to resolve their own ambivalence. One thing that can help with this is if somebody else can find something to approve of, something to be pleased with. It doesn't have to be an achievement - it can be a personality trait that indicates that you find him acceptable somewhere. Without this, I think it's pretty difficult to make the communication work at all. We need to consider how people react to anything that is official. Parent reactions to interpretations that people in the educational area are giving them about their child are likely to have some antecedent in their own earlier experiences with schools, teachers, principals, discipline. Their own school days, in short, come right with them when they come back for a conference in a school setting. This is one break that we have here at Sheltering Arms, I think, and they certainly have it also at the Day Activity Center - we don't look so much like a regular school, and this in itself gives us a freer opportunity to relate to the parents. If you want an example of this reaction to officialdom, think about how you feel when you are out driving and the squad car signals you over to the curb. What are your predominant feelings at the moment before the policeman comes over and waits for you to roll down the window? Most people, I think, feel a combination of apprehension, resentment, righteousness, guilt, anxiety - depending on what they have done. Even if they haven't done anything, these feelings are likely to be there, in most of us. This may be what parents many times feel as they come to anything official for information or interpretation.

There are some differences between the studies that parents seek and those which are imposed on them. When a parent really wants to talk to a teacher about a problem and calls up and says, "Mrs. Johnson, I wonder if I could come in sometime this week and talk to you about Jimmy?" you have a truly motivated parent. When it is the teacher who calls and says, "Mrs. Jones, I wonder if you could come in sometime this week because I would like to talk with you about Jimmy?" the mother may feel, "Oh, good heavens, what has he done now?" This can be a hurt feeling, or a "being called on the carpet" feeling. When the study is initiated by the school and not by the parent, there may be some very good reasons for this, but the parents don't know them. It may be that the problem exists only in relation to school. This

wouldn't be apt to be true with retarded children, although it might be with higher level retardates who seem to their parents just like other children - who may, in fact, be just like other children until they are faced with academic learning tasks. If it is an achievement problem or a problem of adjustment to the group, the parent may have very little reason to be aware of it. It may not be a problem in the settings in which the parent sees the child. If the problem is in the personality area, as it often is in studies of normal ability children, the parent may not be aware of it at all - or, if he is aware of it, he may assume that that is just the way the child is and there is nothing to be done about it anyway - he's stubborn, just like his father, or fearful, just as I always was, or shy, just like his great-aunt Millicent used to be. Many times people accept these traits in children as just being the basic way the child is put together. You can't fix it anyway, so live with it. Another thing that happens is that parents, especially parents of retarded children, have learned to live with their problems too well, whatever the problems may be. They have become so accustomed to the problem that they don't know any longer what it is that they are adjusting to. This is true with many of our most difficult children. The parents would not describe a child's behavior as being out of line because this is the only behavior they have ever seen him show, and they are so accustomed to it on a day to day basis that they simply don't label it a problem. That's just the way he is; they live around him; they don't focus on the problem. They focus on making a big circle and avoiding impact with the problem behavior. I recall a diary that one of our mothers wrote about her very difficult six year old when he first started school here several years ago. She described what he had done this particular week-end and mentioned that he had put a plastic dish on the stove, turned on the gas, and melted it; he had spilled a big box of soap flakes on the kitchen floor because he wanted to help wash the floor; he took the varnish off the dining room table; he pulled down the draperies; he broke a lamp. Then she said this was a typical week-end. Well, for most of us with a six year old child in our home, this would not be a typical week-end and we would be sure it wasn't. But if you have lived with this for six years, this is just the way he is. You get blunted in the acuity with which you can observe, and your standards of expectation shift to match what actually happens.

Generally when parents themselves seek the study they have defined the problem for themselves. They may want to be contradicted, if it is a retardation problem. They want you to tell them something different, but they know. Nearly always, parents of reasonably normal ability have labelled a retarded child of the trainable level as being retarded before they seek the study. This is less likely to be true of the educable child unless he also has other developmental problems. If his speech is poor, if his motor skills are markedly poor, if he has behavior problems, or if he is one of the hyperactive ones, parents may have known there was something wrong and may have partly defined it for themselves, but probably not as clearly, because the closer the child is to normal, the more doubt there is in the parents'

mind as to what other things might explain his behavior.

Another problem with some of the higher ability retardates is that in many instances, they are very much like their parents who may also be mildly retarded. When this is true, these children may be very much like other members of the family and do not present any problems at home; they are not defined by their parents as having problems. But they may be problems to education, because they don't fit the kinds of programs we set up for normal children.

Another factor in the parents' awareness of the retarded child as a problem is how many other problems they have to be concerned with. Some multiple-problem families have a hard time paying much attention to one child because there may be several other children also presenting some difficulties and many other things in their situation demanding attention. In one of these multiple-problem situations, it isn't strange that the parent doesn't always focus on what seems to us to be the major problem, because there may be ninety-nine other things that take priority - and rightly so - in the home situation. I think that we many times expect parents to be awfully noble in paying attention to what we see as "the" problem, when the minute they get home and shut the door behind them the whole place may be exploding with problems. How do you find out if the parent is going to be able to listen and discuss this child with you? There are some clues which may be helpful. One good thing to do is to ask a very general question and see where the parent takes it. Don't say, "How does Johnny get along at home?" Say, maybe, "How do things go at home?" Keep it deliberately vague. If the parent says, "Well, Johnny is really quite a problem. We give him a lot of attention because he is just so difficult. From the moment he gets up until we finally get him to bed, we always have to be concerned about what he's up to." Okay - this parent is with you. She is thinking about Johnny and she is ready to think about Johnny. Or you might ask this general question about how things go at home and the parent might answer something like this: "Well, of course Johnny is pretty difficult, but now lately I have been concerned about Susan, too. She is just having a terrible time in third grade (or high school, or whatever), and our older boy seems to have fallen in with a very bad crowd, and I don't know - my husband is working a double job because we are trying to take care of those old medical bills, and it just seems as if I can't take it." Here you have a picture that is very different from the parent who is willing and able to talk about Johnny. This second mother has a host of things that she needs to talk about and must talk about; you will only frustrate each other completely if you say, "Well, now let's get back to Johnny," because she can't get back to Johnny. She has to ventilate and so you say, "Tell me more," or "What's up with Susan?" or "What kind of wrong company is your older boy mixed up with?" You go where she takes you because this is how you can learn about the hierarchy of problems in this family. Of course, on a different day, this same mother might be able to talk about Johnny and then you wouldn't learn about these other things.

This would be too bad, because really you need to hear about them if you are going to be maximally useful. You need to know what the context is like, because it isn't just a matter of Johnny and his mother, or Johnny and his teacher - it's a matter of Johnny within the whole family. I really think these general questions can be very useful. If you find the mother ready to focus on Johnny, ask her another general question, rather than a specific one. "Tell me how things go for him, day to day." Vague? Yes, it is; you are asking for information. Some parents who are pretty insecure and perhaps a little compulsive will say, "What do you want to know? What kind of thing do you want me to tell you about?" One good answer to this might be to say, "What concerns you most about him? What bothers you the most?" This makes it sound a little more specific, but you are asking for both data and feeling. If the parent very quickly goes into other family problems, this may be a clue that these are bigger and more important, but there is another possibility too. It may be that the other problems aren't so important, but the parent doesn't really want to talk about Johnny and probably doesn't want to hear that he is retarded. She may be using these other problems as a kind of smoke screen to keep you from finding the opening to talk about Johnny. You have to make a decision as to what the situation really is for this particular parent.

If both parents are present, another thing you want to notice is the interaction between them. A good way to observe this is to avoid directing your initial opening questions to either parent specifically. Don't say, "Mr. Jones, tell me how things go at home." Look first at one parent, then at the other, and then at the wall as you ask your question and see what happens. Does the mother look at her husband and say, "You had better talk first," or does the father look at his wife and say, "You'd better do the talking." How do they divide the responsibility? Who seems to have the authority in this team? If they take turns, as they sometimes will, do they do it politely? Or do they contradict each other? If they disagree, as they often will, what's the emotional overtone of their interaction with each other? More often, in my experience, it is the father who is not willing to face up to the retardation and who may be trying to find excuses for the child's behavior. Many times you realize as the parents are reporting to you that these are things about which they have argued a million times before. Sometimes they will want you to act as judge and jury and tell them who is right. Be careful not to fall into this trap! Often they will ask you directly to "decide" between their two divergent viewpoints. When they do, this must be handled directly by you, too. You can say something like this: "I can't possibly make that decision - I just don't know enough about the situation. But is it possible that you see Johnny under different circumstances? Is it possible that there is a middle ground, but you just haven't found it?" You try to help them think about the problem, rather than go on playing their game of one-upmanship.

If only one parent is present - and this is often the case - be

careful to include the absent one in the conversation anyway. Ask how the father feels about things, what his viewpoint is. In the less frequent situation when it is the father who brings the child by himself, it may be quite important to find out why the mother didn't come, because this is rather atypical. Is it perhaps the mother who can't face the problem?

Be familiar with referral information and what other people have thought about this child, but reserve your own judgment. Keep in mind that records can get mixed up, inaccuracies creep into typed reports. Be careful to check birthdates; a year's difference in age can make quite a difference in interpreting test performances, and a typographical error on a birthdate can happen very easily. In making use of other people's viewpoints about a child, keep in mind that different situations create different bases for comparison. A mentally retarded child in a normal kindergarten group will be described by a teacher who is accustomed to normal children quite differently than he might be described by a special class teacher whose framework of comparison is a retarded group.

Listen to what the child has to say. Mentally retarded children are generally not the most accurate reporters when it comes to factual information - their comprehension is limited, after all. But if you are looking for feelings, wanting to get some insight into the emotional aspects of this child, watching him play and listening to the tone as well as the words can teach you a lot. The youngster who plays with the doll house and dolls gently, lovingly, patiently is telling you something about how he has been treated; the one who buries the dolls headfirst in the sand box and likes to tear their arms off is also showing you some of his feelings although not necessarily showing you where they come from.

Sometimes you will see a parent who seems too disturbed to talk with. When this happens, I think the safest thing is not to talk. There are parents who bring a child for diagnostic study when the parent herself - or himself - is really severely emotionally disturbed. This is one of the risks of the cards-on-the-table policy. There isn't a sure-fire answer to this problem, except that by the time you are ready to give information, you have been talking with the parent long enough to pick up any extreme symptoms of emotional disturbance. These usually show themselves in some behavior - often in language patterns, sometimes in highly nervous, insecure, or frightened behavior, sometimes in excessive "weepiness." Sometimes the parent will tell you that he is under psychiatric care. You may want to postpone the parent conference and ask for permission to call the parent's psychiatrist. You may want to make another appointment for a time when both parents can be present. If the parent who is there insists on having some information right then, you can give some, but you can be careful in pacing it and be alert to how the parent is reacting to it.

Another good point is to be generous in appreciating the good ideas parents have had and put into practice. Many parents have found solutions for problems with their own children and can pass on these solutions to you for you to suggest to other parents. If a parent has really had a good idea for keeping a child occupied or handling a discipline problem, recognize this and appreciate it. Your approval will be rewarding to the parent.

We have to come to the area of recognizing failure. You will not be successful in every parent conference. You will rarely be a total failure, but there will be many times that you will fall short of total success, too. There will be times when people will misinterpret what you say and you will be misquoted. It is true that early interpretations about retarded children do need to be made with some caution, especially at the higher ability levels closer to the normal range, but this doesn't seem to me to be an adequate reason for not making interpretations. I think we can feel quite secure when we have good social histories, good medical history information, and good psychological evaluations in making some predictive statements about what to expect from the child. Of course we can't blueprint the child's whole future life, but we can help prepare parents for what is most likely to be the developmental pattern. We have seen lots of evidence that parents who receive early interpretations about a retarded child are able to resolve their emotional problems more successfully and adapt their expectations to his ability better than parents who don't get information until the child is already of school age. Of course there may be some differences, too, in the kinds of parents who seek professional help sooner.

I would like to talk a little about the value of written reports. Here I am thinking of the report of a psychological evaluation. Personally, I am very much convinced that a follow-up letter to parents, covering essentially the same information that was given in the conference, is extremely useful. This is commonly not done by psychologists, and for a very good reason - they don't have time. It is time consuming, especially when you are relatively inexperienced. A letter to parents which will be useful, which will be written in English and not in "psychologese," which will be factual and informative, can be read more than once and can be reviewed at later times. School psychologists in general very rarely can take time for such letters; their service is primarily for the school with benefit to the parent being something of a by-product, although an important one. In any kind of private diagnostic study sought by the parents, however, benefit to the parent is very much the point, and the written letter is very important. As you know from listening to these lectures and trying to take notes, you can't write everything down and when you try, you miss part of what you're listening to. If you just listen, you know what happens - you forget part of what you heard. When one parent brings the child to the study and has a conference, she goes home and tries to tell her husband what she heard, and there's a lot she can't remember. One thing that concerns me is the widening gap between

parents which can result from the fact that each of them has received different information about retardation. Typically, it's the mother who first makes the diagnosis and often seeks the professional help. It's often the mother who goes to MARC meetings and reads the books. Why? Because it's the mother who has to do more living with, more training of, more planning for the child. Often the father can't take time to go for the initial study and conference, and often is unwilling to think about retardation and is trying to deny the problem. So the parents go in very diverse directions, which I think is very bad for the marriage, probably bad for the other children, and not good for the parents as people. A written report does not solve this problem, but it helps. At least the father can read the letter and find out what was actually discussed at the conference. People in a conference situation are very often psychologically hard of hearing; they can hear only what they can tolerate hearing. When the written report arrives, they can take as much time as they need to read it, they can read it again, they can call up and ask questions about it. Many parents report that they have read and re-read reports and that this contributed a lot to their understanding of the child.

Some people say that written reports are dangerous because it is possible for words on paper to be misinterpreted. I think this is mostly rationalization; it seems to me that the likelihood of the written word being misunderstood or misinterpreted is at least no greater, and probably less, than the likelihood that the spoken word will be misinterpreted. These critics of the written report then say, "In the interview situation, you can ask questions if you don't understand." This is true, but doesn't tell us how many people do ask the questions. Many parents in a conference, perhaps a little uneasy and uncomfortable, nod their heads in agreement when really they don't understand, although it is true that their confusion could be cleared up if they asked the right question at that point.

Teachers' reports in writing have a similar value. Teachers are reporting on progress, change, interest development, social interaction patterns, the teacher's view of the child in the situation. These are things which parents ought to be informed about. Often teachers can play an important role in suggesting things that could be worked on at home, skills that the child needs to be practicing, which perhaps the parents haven't thought about - something as simple as having the child learn to butter bread for himself, for example.

Let's talk a little now about parent education programs; here we are thinking about a group orientation rather than the individual counseling and conferencing. Obviously, we think there is a place for both. We have two purposes: first, for the parents themselves to learn to understand their child better, manage him better, and plan more wisely for him; second, to help parents expand their own mental horizons and get a more adequate picture of the whole field. They start by thinking about their own child, his ability level, his problems, his place in their home; they are not thinking about him as

part of a group. The broader parent education program can give parents some more complete and meaningful frameworks in which to view their own child. If we ask where society is going with retardation problems, one answer is that it is going wherever people decide to take it. This decision, in turn, is largely determined by information, understanding, willingness to work on the problem. One of the important reasons for group programs of parent education is to upgrade the total level of information and comprehension in this area, so that projects which become society's projects are based on sound thinking and sound information. What kinds of information should parents have? What we know about causation, mental growth, mental measurement, education, curriculum content, and outcomes. Certainly much information about behavior management and development has pertinence. Most parents of trainable children need to know what have been the outcomes in the past for other trainable children. This does not mean that outcomes in the future will be exactly the same, because community attitudes change and community facilities develop, and we would expect outcomes to change also, but even so, most of us who work with trainable adolescents anticipate that as adults, few of them will be self-supporting except in very protected and limited ways. This is not true for educables, and I think we need to make this clear to parents. We also need to make it clear that these groups of "educable" and "trainable" ability level are not as clearly separated as the terms would suggest. There are many educables who are poorly equipped for competitive employment, and there are some trainables who do better than we would expect. Despite the exceptions, however, this is still useful "framework" information. I think we need to explain our school programs carefully because so many parents think of school only in terms of academic learning, and they need to broaden their definition of school. I think parents need to know about follow-up studies. They need to know more about the emotional aspects of living; they need to know that retarded children have feelings which are often more sensitive than their ability to discuss them, explain them, verbalize about them or interpret them. They need to know that children, by and large, transfer their affections as the situation demands, so that many a child whose mother knows could not be happy away from her goes to the institution and is perfectly happy. It is more likely that it is the mother who can't be happy without the child, because she has become so overly invested in the child that she can't pull out. There is nothing to take up the time that she, for ten or twelve years, has been investing in the child. Parents need to think about behavior, how it develops, how it gets structured, and what the rewards are. When children show behavior we don't want them to show, we try not to use punishment as our first line of attack. Rather, we try to see what this is about. What is he getting out of it? Where are the rewards? If we can figure this out, we have a much better idea of how to steer the child in the direction of behavior which we do want. We need to help parents understand overprotection, the attitudes as well as the behavior. Many times parents feel that a child is inadequate to do things for himself, so they make him inadequate through their own behavior which expresses their own feelings. Parents need a lot

of help in understanding rigidities, obsessive-compulsive traits, schizoid personalities, autistic trends, and the overlap which these things have with brain injury and retardation. It is useful, too, to focus some attention on adult adjustment and patterns of adapting to conflicts and problems of living.

Even when the parent education program is, on the surface, an information-giving thing, this is not all that is happening. There are some highly important by-products. One of these is change in attitudes. This doesn't happen just because people come; it happens because other people come and they get to know each other and there is some bridging of some of the gaps. People become more accepting of themselves, more accepting of each other, and more accepting of the problems which brought them together. Having a mentally retarded child really is a threatening experience which does have potentially a severe impact on parental self-esteem. Some parents do become actually semi-crippled emotionally. This is not to say that other unfortunate life events might not have produced the same result for these particular parents, but surely having a retarded child is one such life event. When you see parents "pulling out" of the emotional damage, as many of them do, with the support that they get from each other, you do appreciate the values of group experience. There is something contagious that happens; one parent feels the strength that another parent has built up and makes a new start at building his own strengths. Along with group meetings there is usually some sort of social hour or coffee time and this is a time when a lot of parent to parent help takes place. Also, along with group organizations you usually find some fund raising projects. Many an emotionally mature father who has worked at a rummage sale all day Saturday has also been active doing group therapy. He'd never call it that, but if he has come to terms with the retardation problem, he has something to contribute to other fathers who haven't made as much progress with their own problem.

A few more things come to mind about the group education. In making suggestions to parents in a group, you do have to be careful because you don't have the data. You can't possibly tell a group of fifty parents what they should do about their children's behavior, because you can't know which factors are involved in which cases. You can tell them general principles and give some examples. Parents in a group will often ask a very specific question and this may be a signal that they need help, but this isn't the time or place that much real help can be offered. This doesn't mean that you ignore the question, but you may need to find another time and place to answer it. Many times you can make general suggestions in a group, however, which are related to a general principle. For example, if a parent begins a question by saying, "We have to..." "We have to lie down with her or she won't go to sleep." "We have to sing to her or she won't eat." Mostly always, they don't "have to." For some combination of reasons, they want to, even though they don't interpret it that way. When you get on the track of the reason then you may be able to help. Another

thing that you can help parents with is to help them accept children's emotional outbursts. We have one youngster, for example, who is the oldest of several children in the family. One thing that has happened to him at home is that it is easier to soothe him (and give in to him) than it is to manage him. But of course this is not going to solve his problem. Another thing that parents can make progress with is learning to accept a child's needs to express his feelings. If you can help parents think in terms of giving a child opportunity to be angry without being criticized for it, you can help create better emotional health in families. This is a place to talk about water play, finger painting, hammer and nail sets, punching bags - things that offer vigorous outlets or soothing outlets. Puppets and dramatic play have possibilities here too. Still another thing that parents can benefit from is the idea of helping children practice ahead of time for new experiences - a "walk through" preparatory practice session. If the child is going to go to a residential camp for the first time, it is a good idea for parents to take him to see the place and perhaps meet some of the people; it helps for parents to spend some time in advance talking about camp routines - not too specifically, because they may not have the information - but to give the child some idea of how the schedule will work, the kinds of activities he will be engaged in, so that he develops some "feeling" for how it's going to be at camp. The same thing holds for preparing children for other kinds of new experiences - going to have their tonsils removed, eating in a restaurant, taking a trip by train.

This whole area of parent counseling and parent education is a vast one, obviously, and a very essential one. We won't succeed 100% with all parents, any more than we do with all children, but we can surely improve our methods and learn from our experiences. Many of us in the field of retardation believe that what we do with parents is as important, and often even more important, than what we can do for their children.

GENETIC ASPECTS OF MENTAL RETARDATION

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Although I've known about Sheltering Arms for a long while, this is my first visit here and I am glad to become acquainted with this very interesting and famous place.

The Dight Institute is at the University of Minnesota. It was named for a doctor in Minneapolis who was famous for several things. The feature about him that interests most people is the fact that he lived near Minnehaha Falls in a house on iron stilts, sometimes called a tree house. It is thought that he did this because he was afraid of grass fires. He was the man who was responsible for getting the first milk pasteurization law in the city of Minneapolis. He was interested also in man's genetic heritage and, as a result of this, when he died he left a bequest to the University of Minnesota if it would set up a center for human genetics along three lines: teaching, research and counseling.

We are carrying out these functions. There are classes in human genetics at several different levels - for undergraduates, for graduates and for those who are in research. In terms of research we are particularly interested in genetics related to the nervous system and its functions.

Counseling meant the application of genetic knowledge to people who need to make decisions. Some people come to us before marriage with the statement: "I'm in love with my first cousin." What we tell them usually does not alter their decision, but none the less we do point out that the risk that their children will have some serious problem is somewhat higher than if they were to marry someone else in the population. Others come in before marriage because there is a history of a severe neurological disorder, blindness or some other problem in the family and they want to know what is the chance that it will be passed on. After marriage, people come if they have had a child with some serious defect and want to know what is the chance that another child will have the same problem. The services of the Dight Institute are available without charge and should you come across a problem for which you want information, we would be glad to help you.

The field of genetics is a very interesting field. You can't read very much these days without hearing about DNA, for example, which is now known to be the genetic material. Sheldon Reed, who is the director of the Dight Institute, and I attended a symposium

at Gustavus Adolphus College last week. The topic was "Genetics and the Future of Man." The first day's talks had to do with the scientific background - what we know about genetic change and what we know about changes in the environment that increase the rate of genetic change. The second day considered the religious, moral and sociological aspects of the problem.

Genetics as a field of study stretches all the way from basic events at the level of DNA molecules to the enzymes and structural proteins that are made by the genes and then to the effects these have upon the developing organism and the function of the mature organism. One can then go on to topics, such as racial differences, which have a genetic basis, but which lead to problems which are primarily cultural.

What I want to do today is talk with you about some aspects of genetics, how geneticists would approach problems. Then I will apply this specifically to what we know about mental retardation. One of the problems that almost always comes up when we talk about genetics has to do with the relationship between heredity and environment. You realize that it's nonsense to ask the question, "Heredity or environment?" Every trait that we have requires both. It is true, however, that in some traits the differences between individuals are primarily genetic and in other traits the differences between individuals are primarily environmental in origin. But to understand the development of traits we must take both into account. To illustrate this specifically with reference to mental retardation, I have recently written a chapter which surveys fifty distinct genetic types of mental retardation. It is obvious then that each of us here has those genes functioning normally. If any one of these genes were abnormal, you would not be here, or if you were here, you would be on the receiving end of the line. The presence of a normal brain requires the cooperation of 50 genes (or more, for there must be many others we have not yet identified).

How does environment enter into this? The first hand-out page (Table 1) is taken from an article by Goldfarb, setting up two possible conceptual models. In the first of these we can envision a child with brain damage. That brain damage could be the result of primarily genetic factors or it could be the result of traumatic or infectious disease. Such a child, living in a normal family, has a reduced capacity for receiving signals, or integrating them, or producing responses. This child then appears different to the parents. The parents are puzzled by this and will respond to this child in a way that they would not to other children. There is thus a feed-back loop which accentuates the problem and thus leads to the remaining steps.

The second model is a different one. Here Goldfarb envisions

a child who has an intact physiology but is in a family setting that is highly abnormal. The child puts out the normal signals but does not get a normal response. The child, therefore, develops an abnormal response, and this is further accentuated by a feed-back loop which is very much like that in the first. These two models don't account for all possible situations. The difficulty is that when we are confronted with a problem child, it is usually quite difficult for us to say whether we are dealing with model A or model B. Nevertheless we must keep both models in mind and realize that the full range of behavior that we observe in a given child is in some way the result of interactions between the genetic potential and the environment of development.

Fortunately, a lot of interesting work has been done on experimental animals. I visited Jackson Laboratory at Bar Harbor, Maine this summer. Much of the work done there has pointed out the importance of early experience. I saw, for example, one dog that had been reared in isolation from the time of weaning. They have cages where a dog can be kept very nicely, fed, watered, and all of its needs taken care of, but never see a human or another dog. When this dog was put into the test arena, the dog did not leave the cage. The dog was chained by inhibitions as effectively as if there were a metal chain around its neck. This laboratory is also experimenting with the way in which different breeds respond differently to effects of isolation.

Generally, then, the genes provide us with a certain repertoire of responses. Some of these responses will never be expressed unless they are called forth by the appropriate environment during a critical period in development. If the environmental stress comes too early or too late it is ineffectual. We do not study, therefore, the inheritance of behavior per se but a more complex relationship between genes and experience.

Let us now turn to the Table 2 listing some genetic variations affecting the blood. The blood is an important tissue in the human body, and it is easily accessible. As scientists have looked at the different components of blood, they have found that everyone of these has some genetic variation. For example, starting at the top, we can look at the red blood cells. Hemoglobin is a complex molecule, made up of an iron containing portion which gives the red color to the hemoglobin and then a protein part. There are a number of different types of hemoglobin. Hemoglobin A is normal adult hemoglobin. Hemoglobin S is sickle cell hemoglobin, a type which has a fair frequency among certain Mediterranean people and among those in northern Africa. When this gene is present in double dose, the person has a severe anemia and seldom reaches the age of reproduction. A single dose of this gene, however, makes the person fairly resistant to Malaria. One dose of the gene is an advantage in a malarial region,

but two doses is a disadvantage under any circumstances. These two hemoglobins (A and S) differ from each other only because at one point in the molecule there is one amino acid instead of a different one. This different amino acid in hemoglobin S gives a different electrical charge to that part of the molecule, so that under conditions of reduced oxygen tension the molecule folds on itself. This folding of the molecule makes the whole cell fold, so it assumes a sickle shape. The liver and spleen recognize this strange cell as something that shouldn't be there and take it out of circulation and destroy it, thus giving rise to an anemia. As the scientists have gone on they have named hemoglobin types by letters of the alphabet. They have already used up all of the letters of the alphabet and more variations are being discovered. Here, then, is one way in which bloods differ.

If we look at the red cells again, there are some enzyme differences. About twenty years ago in Japan an eye, ear, nose and throat specialist was using hydrogen peroxide on the nasal sinuses of a patient. Usually a frothing is produced. In this case, however, there was no such frothing and the nasal membrane turned a dark color. The doctor was sharp enough to realize this person might be different. He knew that the hydrogen peroxide issues were broken down by an enzyme in the blood called catalase. So he did a determination and found that this person had no catalase in the blood. (This is what the word Acatalasemia means.) It had been assumed that this enzyme was essential for life, but here was a person living in quite good health. It turns out however, that about half of the people with this genetic trait have ulcerations of the lining of the mouth or the nasal passages. The other half appear to be essentially normal. So here is an enzyme which is normally present, but if the gene* to make it are not there, the enzyme is missing.

The second enzyme deficiency listed (with a very long title) makes people abnormally responsive to certain drugs. Certain of the anti-malarial drugs will cause a break down of the red blood cells and thus jaundice. It is interesting that drugs do not have the same affect upon all of us because we have different enzymes.

The next point is already well known to you, I think. There are antigens on the red cells which are responsible for blood type differences. It is possible, therefore, to type red cells for many different factors.

. As we continue you will notice there are some differences in white blood cells. They may have different kinds of shapes which are genetically determined. It is possible to type for white cell type, not just red cell. There are some people who have a genetic disease leading to an absence of certain kinds of white cells. So we begin to realise that if we have a normal white cell count, it's normal because there is a genetic mechanism for keeping it

normal. If there is a mutation for certain genes, we will either have too many or too few of certain types of white blood cells.

Let us go to the fluid part of the blood, the plasma. In Table 2 some of the components are listed. You notice two columns. There is a column indicating rare absence. Some people have almost no albumin, while others have no gamma globulin. The antibodies against disease are carried in the gamma globulin fraction, and therefore these children (mostly boys) will be quite susceptible to diseases. There are some who have no fibrinogen, necessary for clotting. There are at least eight different clotting factors. We used to think that all clotting disorders were hemophilia, but this is not true. A number of factors are necessary for the blood to clot normally. The very least item in this column is interesting because the person who has a deficiency of pseudocholinesterase is abnormally susceptible to some drugs used as muscle relaxants. If one of these drugs is used as an anesthetic the person will stop breathing, and artificial respiration will have to be maintained for a long period of time until finally the drug is broken up by the body.

The last column points out that we have common differences from one person to the other. Almost all of us have haptoglobin, but we differ in our haptoglobin type (or in our transferrin type or Gm type or Ag type). These points may seem a long way from mental retardation, but I wished to indicate some of the ways in which genes make us different.

Table 3 points out something about the ways in which genes are transmitted from one generation to the next. I have picked out for purposes of illustration the X-linked recessive traits. This would be the pattern for classic hemophilia and you may know something of how it is passed on. This type of inheritance has certain rules which can be determined by looking at the family carefully. Genetic transmission is not vague. Different patterns of inheritance have precise rules. You will notice that the first pedigree drawing shows what appears to be an oblique transmission. (One reads a pedigree by remembering that men are squares.) The trait is passed through carrier women to one-half of their sons. The bottom pedigree shows how it is possible to have an affected female if her father is affected and her mother is a carrier.

How does this apply to us as we take a family history. There is sometimes a temptation to look upon a family history strictly from an environmental point of view - the family setting, the cultural forces leading to a given problem in a child. You should realize that sometimes a better interpretation will be a genetic one or some combination of genetic and environmental.

There are rules for deciding which interpretation is better in a given case. A man in the dental school has been tracing a

little bump on the inside of the jaw, and has examined over 500 people. This trait appears in about 8.5% of women and about 5% of men, an obvious sex bias. It is transmitted directly from parent to child and thus would be a dominant trait in the genetic sense. We wondered whether this could be an X-linked dominant. If there were an affected father, he has only one X chromosome and the gene would have to be on that one. Among his children, all of his daughters get that X chromosome in order to be daughters. So if it were an X linked dominant trait, starting with an affected father, all of the daughters should be affected and none of the sons. The data clearly showed that it cannot be an X-linked dominant trait.

Table 4 lists some suggestions for planning a genetic study for reading a report. It doesn't make sense to study the genetics of something unless we have a way of defining it, of diagnosing it. That diagnosis should not include the family history. It's possible to study the genetics of some trait if you have used the family history to make the diagnosis. We call the index cases (the affected persons that we study) the probands and these have to be identified clearly. There are some problems with bias which have to be taken into account. In some cases we need to have a control group, but in all instances we must study relatives. It is impossible to study the genetics of single individuals. Finally there are certain guides for the analysis of the data we have obtained.

Now the last feature that I've not talked about has to do with chromosomes. I wonder how many of you have seen pictures of human chromosomes. Human chromosomes were first clearly identified and photographed in the year 1956. It was in 1959 that we first learned that Mongolism resulted from an extra chromosome. Here is a picture of chromosomes from a mongoloid child. If you count, you would find that there are 47 chromosomes instead of 46.

Very briefly, how do we get a picture like that. A sample of blood is taken in the normal way. This is permitted to settle or is put into a centrifuge. The bottom half of the tube is made of red cells, there is a thin layer of white cells, and then the top half is clear plasma. It is the white cells that are taken, for these cells have nuclei. When that little layer is put onto a culture medium in an incubator the cells will divide. After three days, a drug is put in to stop division. These cells zip through cell division quite fast, but if we can stop them halfway through, then the chromosomes are just right to look at. A photograph is taken and the individual chromosomes cut out. The chromosomes vary in length, and they are numbered in order from the longest to the shortest. They also vary as to the position of the attachment region.

In most cases of mongolism the chances for the next child to

have the same problem is about 3 per cent. In a few cases the mongolism is of a translocation variety, and then the risk for the next live born child to be mongoloid is 33%. That's quite a difference, between 1 in 30 and 1 in 3. I have here a picture of chromosomes from the grandmother of such a mongoloid child and you can see circled in red here the double chromosome. You can see that there are two of the little attachment regions. Two chromosomes were connected end to end. This picture emphasizes the fact that chromosomes can be seen, that they can be identified, and that this information is useful.

There are several other syndromes involving chromosomal anomalies. One in the 13-15 group and the other involves chromosome 18. If there are three number 18 chromosomes, the child is severely malformed, is severely retarded and seldom survives more than one year of age. There can also be differences in the number of X chromosomes or Y chromosomes correlated with problems in the function in the nervous system.

Other types of mental retardation arise from disorders in amino acid metabolism. The classic one is PKU. In this case, the body does not have an enzyme which is needed to handle the amino acid phenylalanine. The mechanism can be compared to a river running downstream. If a dam is put into this river, two things will happen. There will be too much water above the dam and too little water below the dam. In PKU there is too much phenylalanine that accumulates in the blood stream, and apparently this is a major reason for the damage on the nervous system. The answer to the problem is to slow down the river upstream by providing the child with a diet which has very little alanine.

I am currently involved in a research project in ketonuria which may have some implications for what you are doing. This disorder has two effects upon the nervous system. One of these is to clobber development. It's not clear exactly how this is done, but the brain is seriously disturbed and irreversibly so. If the child is not put on the diet until after one year of age, the IQ is very low. But there is a second kind of effect which could be called toxic or pharmacological. There is sometimes a child on the diet who will manage to steal food. The mother has the impression very often that the child after eating the cookie or drinking the milk becomes more hard to manage. For the most part, this is a general impression. We have recently tried to test this more objectively by having children in the hospital and altering the diet while under supervision and careful psychological examination. Within three days after diet change the child is noticeably different. One of the tests is a self-winding calendar wrist watch altered so that the movement of the child's hands directly moves the dials. This then provides an objective measurement of activity. For several children the activity level doubled when put on the extra diet. We are now looking for other

objective measurements of change in behavior.

There also are disturbances in carbohydrate metabolism, disturbances in fat (or lipid) metabolism, and some other types of retardation in which we don't yet know the biochemistry, but by studying the family pattern, we can be sure that genes are involved. These, for the most part involve severe retardation and such can be described as due to a single gene.

It becomes somewhat more difficult when we look at the mild retardation cases and try to understand the interaction of genes and environment. We might make a parallel with differences in body weight. Would you accept the idea that body weight is the result of an interaction between genes and environment? There is a strong genetic factor for height, and height enters partly into weight. But you know also that weight can be modified by means of diet, so here is the interaction between these two. It seems extremely likely that in a similar sort of way genes and environment must interact in bringing about the full range of distribution on an IQ scale.

The genes do not specify an IQ for a person, but set up a probability distribution. With an average kind of education, my actual IQ is most likely to be in the middle of this curve. If I have very good training, then I'll measure higher, but that's less likely. And if I have a poor training, I measure lower, but that's also less likely. The actual measured IQ depends upon the effect of experience and training.

Now let me refer to a study at the Eight Institute which is now in publication. It is based upon a study of about 300 families of mentally retarded persons who were in the Faribault State Hospital about the year 1915. Careful family histories were done at that time and they have now been followed up. The strategy was to start with the person who was retarded in the hospital, go back to the grandparents and trace all descendants. In these 300 families we have information on about 80,000 relatives. There are two major findings. The first of these has to do with the fear that we are becoming more stupid each generation. You know that in a school setting the children with lower IQ scores come on the average from larger families. This gives us the impression, therefore, that the genes for low intelligence are being accumulated at a more rapid rate than the genes for higher intelligence. It now turns out that this is a simple error in the collection of data.

We have IQ scores of parents at the time they were in school, so that the scores for parents and children are at similar ages. The parents of low IQ did have more children than the parents with high IQ scores, but something has been omitted by this because an error is introduced by limiting the analysis to parents. In other words, the brothers and sisters of the parents who did not reproduce

were omitted. When they are put back into the analysis, we find that there is no bias. As a matter of fact, the individuals in the parent generation with IQ's of 130 or over have slightly more children than those with IQ's of 70 or below. So this fear of a continuing fall in IQ turns out to be unfounded.

The second point has to do with the transmission of retardation from parents to children. When both parents were retarded, 40 per cent of their children were also retarded and only one percent had an IQ of over 110. In other words, this is a markedly skewed curve. Parents like this are not likely to come into the Dight Institute for counseling, but they are well known to the social service agencies for a variety of reasons. This leads to a question for which I have no answer. What responsibility do we have to offer genetic information to these parents? I am not here making the distinction as to whether the retardation is primarily genetic or primarily cultural. I am simply saying that if one is to predict the results we know that those parents have a higher portion of retarded children. There should be some way that we could find within the limits of a democratic system (respecting individual rights) of helping these people not to have as many children.

We can also look at the data another way. Of the retarded children, 40% had one or both parents retarded. The point is that there is a transmission of genes and culture in such a way that retarded parents beget retarded children with a high proportion. One other point that I haven't stressed here has to do with the 1% of the children where both parents have IQ's below 70 and the child has an IQ of 110. That's rather tragic too, isn't it? We have at present no legal procedure of doing anything for the child. After all, if they have a house and if they have food we cannot intervene, but this certainly is not an adequate setting for the development of the abilities that child has.

Perhaps I should stop here. I would be glad to answer any questions. I have tried to tell you something of what we know about genetics, the tools that are at our disposal, with a brief application of this to mental retardation.

Answer to Dr. Blodgett on PKU:

If PKU is in the population at the rate of 1 in 10,000, then we know that one out of 50 people is a carrier. So if you have fifty people, chances are that one of them has a single dose of the gene. Now the child with the disease who has been treated and grows to maturity has both genes affected. If he marries, there is one chance in one hundred for a given child to have phenylketonuria. Now in terms of the family itself that's a fairly low risk, but every child will at least be a carrier. Here we have a

conflict - from the point of view of that individual person who wishes to have a child, the risk of having an affected child is low. But this will, in a slow way, increase the frequency of the genes in the population.

I have indicated to you already that in genetics we trace the pathway from genes to traits. In the development of an organism, we need three factors: raw materials, energy, and information. This is like any building. We need raw materials, (stone, metal and so on), energy (men and machines), and information in blue prints. The information in the organism comes from the genetic material. Now how can genes provide information of this kind? Remember I mentioned for hemoglobin S that there was a difference in one amino acid. Apparently what the genes do is to specify a sequence of amino acids for a given protein. Some enzymes, for example, are made out of 200 amino acids in a chain. How many amino acids are there? There are twenty that the body uses, so if you can imagine a chain two hundred beads long with twenty different colors of beads then you have an idea of how that enzyme can be made. All we need now is a strand of DNA which gives the instructions to put the beads in proper sequence. It turns out that when this is done the chain will all by itself fold up into its proper shape to bring about its effect.

How does the genetic material tell what amino acid goes there? The DNA molecule is like a spiral staircase - it has two rungs and it has steps. As you approach this staircase, you notice that on each step, there is one letter on one side and another letter on the other side. As you walk up the right hand side you see there is the letter C, then A, and then T. The next step is T, then A and then G. It turns out that the genetic code is in words of three letters each. CAT stands for one amino acid and TAG for another. Now, what would happen if by mistake the first step were changed from C to T? It would now read TAT and that would be a different amino acid. So that one of the simplest mechanisms for mutation is a change from one base to another. If you change just one letter out of the three letter code, then there is a different amino acid. It may well be that this amino acid is important for the way the enzyme folds. If it folds the wrong way it can't do its job.

Some other kinds of mutations are much bigger than this. Radiation can knock out a piece of DNA. Or it may be that the whole chromosome is broken and then becomes lost in cell division. This kind of mutation is probably so severe that the embryo will not survive. It's somewhat self correcting in this way, since the greater the mutation, the less likely that the organism will survive.

Table 1

CONCEPTUAL MODELS IN CHILDHOOD SCHIZOPHRENIA

Goldfarb (1961), Am. J. Orthopsychiat. 31:738-747

A. Child with definite brain damage living in a relatively normal family.

1. The intrinsically deviant child on the basis of somatic inadequacy
2. Diminished capacity for receiving and/or integrating incoming signals and executing the appropriately adaptive response to these cues
3. An ego deficient or deviant child with behavioral aberrations
4. Defect in personal identity and in awareness of differentiated self in action
5. Confusion, feelings of unfamiliarity
6. Primordial panic: hypersensitivity
7. Defenses: especially selective or total withdrawal, symbiosis, seeking for sameness

Impact of child's
behavioral aberration
on parents

Response of parent (hypo-
stimulation or hypersti-
mulation) enhancing
behavioral aberration of
child

B. Child with intact physiological equipment but living in a highly aberrant family.

1. The deviant psychosocial environment of the family, especially situational and communicative confusion and formlessness (parental perplexity)
2. Absence of an organizing environment with nonreinforcement of desirable ego traits, or reinforcement of bizarre
3. An ego deficient or deviant child with behavioral aberrations
(Remaining steps same as above)

SOME GENETIC VARIATIONS AFFECTING THE BLOOD

Red blood cells

1) Hemoglobin types (A, S, C, D, E, G, H, I, J, K, L, K, N, O, P, Q.)

Quantitative differences (thalassemia)

2) Enzyme deficiencies

Acatalasemia

Glucose-6-phosphate dehydrogenase deficiency

3) Red cell antigens (ABO, MNS, Rh, P. Lutheran, Kell, Levie, Duffy, Kidd)

White blood cells

1) Variations in shape of nuclei

2) Leucocyte antigens

3) Agranulocytosis (absence of certain types of white blood cells)

Plasma

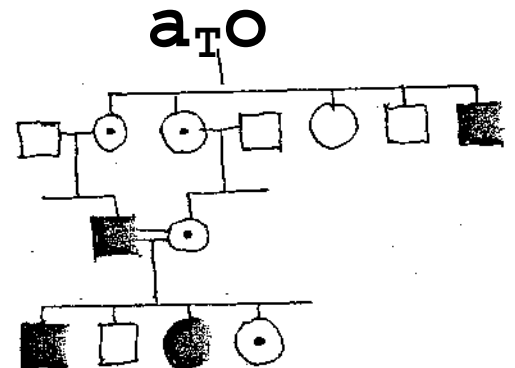
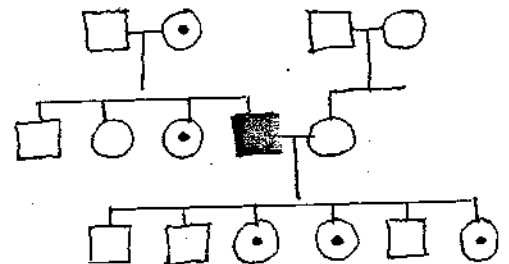
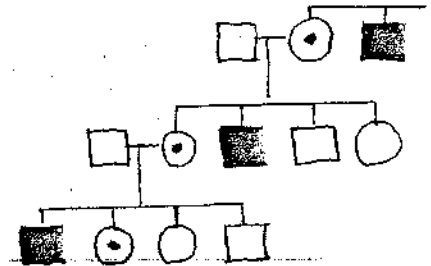
Component	Rare absence	Common variation
Albumin	Analbuminemia (Double	
Globulins		
Alpha	Ahaptoglobinemia (hemoglobin binding)	Haptoglobin types Group specific component
Beta		Transferrin types (iron binding)
Gamma	Agammaglobulinemia	Gm types
Fibrinogen	Afibrinoginemia	
Clotting factors	8 different deficiencies	
Beta-lipoprotein	Acanthocytosis	Ag types
Ceruloplasmin (Copper binding)	Wilson's disease	
Enzymes	Alkaline phosphatase deficiency Pseudocholinesterase deficiency	

Table 3

CHARACTERISTICS OF A RARE X-LINKED RECESSIVE TRAIT

Adapted from McKusick (1962. Quart. Rev. Biol. 37:69) and from
 Morton (1962. In Methodology in Human Genetics edited by
 W. J. Burdette)

- 1) The trait appears; to be transmitted obliquely (rather than directly) from one generation to the next.
- 2) An affected male usually has normal parents, but the mother may have affected male relatives.
- 3) Carrier women are normal, but 1/2 of their sons are affected and 1/2 of their daughters are carriers.
- 4) Except for a new mutation, every affected male has a carrier mother.
- 5) Affected males do not transmit the trait to children of either sex, but all daughters are carriers.
- 6) Affected females will be:
 - a) An XO daughter of a carrier mother, or
 - b) An XX daughter of a carrier mother and affected father (a mating made more likely by consanguinity).
- 7) In the population, the percentage of females affected is the square of the percentage of affected males.



SOME SUGGESTIONS FOR GENETIC STUDIES

The disease

- 1) A clear definition of the disease, limited enough to reduce heterogeneity.
- 2) Well standardized diagnostic technique with minimal observer error.
- 3) Data on frequency of the disease by sex and by age at first diagnosis.
- 4) A list of variables known or suspected to be associated with the disease.

The probands

- 1) A simple representative of the diseased population. Check possible sources of bias:
 - a) Selective policies of hospital or clinic.
 - b) Chronicity. Select cases on basis of first admission.
 - c) Competing risks. Record presenting complaint.
 - d) Family history. Note number of times each family is independently ascertained.
 - e) Exclusions. Report number of potential probands excluded and reasons for exclusion.
- 2) A sample large enough to permit valid conclusions. In general a larger sample is required for rare common diseases.
- 3) Routine record of consanguinity and twinning.

The control group (Not required for rare disease with simple inheritance)

- 1) Matched for significant variables associated with the disease.
- 2) A sample representative of:
 - a) The general population, or
 - b) The population of those not affected with the disease.

The relatives

- 1) For common diseases stress the parents, sibs, and children.
- 2) Check both positive and negative reports - by direct examination or record search.
- 3) Report data separately by:
 - a) Degree of relationship
 - b) Sex
 - c) Age at report (or at first diagnosis for affected relatives)

The analysis

- 1) Sort sibships by mating type (e.g. both parents affected).
- 2) Adapt analysis to method of ascertainment.
- 3) Use genetic concepts (penetrance, sporadic case, etc.) appropriately.
- 4) Avoid decisions as to mode of inheritance unless good data and good knowledge of genetic theory are available.
 - a) Single gene or polygenic
 - b) Sex-linked or autosomal
 - c) Dominant, recessive, or intermediate

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CURRENT PUBLIC HEALTH VIEWPOINTS AND PRACTICES

Dr. A. B. Rosenfield
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Section of Maternal and Child Health
Minnesota Department of Health

I am said to have a very decided interest in mental retardation because I have been concerned with a couple of mental retardation projects and therefore it would appear from what people say that I spend most of my time on them. However, I should point out that among the programs in the division of special services, some of the programs I have are entirely unrelated. In the section of maternal and child health, which is one of chief interest to me, are included nutrition, the four county project for retarded children, accident "prevention, poison information center, human genetics, and a section of mental health, health education and for good measure, the public health library also belongs to me. How it got in my department, I don't know, but it has one advantage, in that I always see all the new magazines and books first.

Before I get into the subject of public health viewpoints and practices, I think I should define a few terms in public health so that you will understand our particular approach. Health is defined by the World Health Organization as a state of complete physical, mental and social well being, not merely absence of disease or infirmity. Public health is the art and science of preventing disease, prolonging life and promoting physical and mental efficiency through organized community effort. The important phrase there is "organized community effort." Public health is concerned with environmental factors and the control of communicable diseases which are part of preventative medicine, as well as physicians, dentists, nurses, hospitals, nutrition, safety, housing, recreation, education, genetics, radiation, social economic factors and a host of others. Public health involves problems that are preventable that concern a large number of people that cannot be met individually and that are amenable to organized community effort. Public health might be said to be the wholesale approach. We are concerned with the entire population, not with any special social or economic limitations, in contrast to medical care which may be called the retail part of the business in that it provides direct service to the consumer. Public health attempts to prove the truth about the statement that an ounce of prevention is worth a pound of cure. It might be differentiated from curative medicine in that we are trying to lock the barn door before the horse is stolen, or the garage door if you want to modernize it, rather than afterwards. I might give you a practical example of the difference between the approach in public health and the clinical approach from the alcoholism program. This program was set up by law; Governor Anderson was the author of

the bill when he was in the senate. There is an advisory board of nine members, most of whom are AA members. There is no doubt that Alcoholics Anonymous has done the best job insofar as rehabilitation is concerned, and physicians have probably done the poorest job. At our meetings every once in a while, one of the board members says, "You remember Joe Doaks who has been dry for five years? Well, last week he fell off the wagon," and then I hear a lurid account of what happened to him and how he landed in the gutter and had to be picked up. This is fine. I can be sympathetic to this poor fellow who has a problem and needs care, but I have no direct interest in him whatsoever from the standpoint of public health, I couldn't care less. He is just one individual. We are concerned in public health with the community problem. The treatment of the one individual requires a medical and social problem. We in public health are concerned with prevention and education. Teachers, by law, are supposed to have training in problems of alcoholism as well as tobacco and narcotics, but as far as I know, no training institution in Minnesota provides them with this education. There is no sense in asking for another law to require it, when what we need to do is to enforce the law that we have. We are concerned with seeing that teachers have the proper kind of training and education, so they will understand what the problem is and what the affects are and be able to transmit this information to the students with whom they are directly concerned. They are not going to change older people's philosophy anymore than people are going to stop smoking. (I have! I'm righteous now!) It's the youth that we are going to have to educate as to the affects of these things and why people make the decision of whether to drink or not and should make it not on the basis of emotional approach, but on the basis of fact. We don't pay any attention to this particular chap who has a personal problem and needs to have something done. The AA's can take care of this situation. We are concerned with the educational program of prevention. This isn't easy to sell, because it is a long term approach and everyone wants to do something right now for the people in front of us.

Now I shall limit myself to discussion of prevention of mental retardation and only one phase of prevention. There are three approaches, biological, psychological and socio-cultural. I shall speak only of the bio-medical preventive measures, under a variety of headings. My first one is research. Everyone admits that it is important, expensive, necessary and a long term approach. Everybody will admit that we are not going to reduce the problem until we can find the cause and remove it, because we are never going to be able to provide enough beds to take care of all the youngsters who are already here, and this number will increase every year. Furthermore, I think it must be clearly understood that mental retardation is not a single, specific condition. It is a variety of conditions. There are some 200 causes that have been identified and yet the physician is unable to make a specific diagnosis in most cases because these 200 causes represent only from 15 to 257. of the cases. There is

only a small handful that is actually understood well enough for a meaningful diagnosis. A few of these are PKU and galactosemia about which we know little, because they are inborn errors of metabolism, and mongolism and cretinism. So, while everybody talks about the importance of research and what has to be done, nobody has time to wait for it because they ask, "What are you going to do for this child in front of me right now?" There is an advisory board on handicapped, gifted and exceptional children of which Dr. Blodgett is chairman. A few years ago when Dr. Maynard Reynolds was the chairman, he told me that he was embarrassed to see me attend meetings regularly because they never talked about health, although the committee is set up to be advisory to the Department of Health, Education and Welfare. He said we ought to set up a program to talk about health at least at one meeting. I told him it wasn't necessary because I was going to come anyway, because some day one of the members would forget himself and mention the word health and I was going to be there when it happened! So far I am waiting. Actually they do talk about health, but it isn't the urgent concern because you can't do anything medically, but these children do need education and rehabilitation and this is what they are talking about.

The next preventative measure has to do specifically with women and maternal infections because maternal infections do cause a variety of congenital malformations, including mental retardation. The one about which we know the most is German Measles, or Rubella, which has received a lot of attention since 1941 when an ophthalmologist of all people in Australia discovered that he was seeing a lot of babies with congenital cataracts, congenital deafness, and heart conditions. They had central nervous system defects as well as mental retardation. In talking with the mothers, he discovered that most of them said that they had been exposed to German Measles the year before when there had been a very severe epidemic in Australia. His paper said that 90% of these mothers who were exposed to German Measles early in pregnancy ended up with a baby with either cataracts, deafness, cardiac conditions, central nervous system disease or mental retardation. As a result of his work, Australia actually passed a law permitting legal therapeutic abortions if the mother had been exposed to German Measles early in pregnancy. This was a retrospective study in that we have the end result here and have to find the cause. Since people in general and mothers in particular are very anxious to find a cause for something like a birth resulting in an anomaly, they remember a lot of things that they can blame it on. So while many of these women claimed they had been exposed, and they probably had been, few actual diagnoses had been made. Some of these were women who had not been seen at the time they had the rash, but they had a rash and it looked like what the neighbor had and the neighbor supposedly had German Measles, so they decided they had German Measles. Studies done since then from the prospective point of view, starting with the woman when she first becomes pregnant and following her through

the pregnancy and after the birth of the child, had not given US this high a figure. It has been found that if the mother has been exposed within the first six weeks of pregnancy, the baby is likely to develop cataracts as an anomaly; if the German Measles occur at nine weeks of pregnancy, the handicap will probably be deafness; from five to ten weeks there is a cardiac condition and a variety of central nervous system anomalies such as hydrocephalus, microcephalus, and mental deficiency. The risk for the mother during the first trimester (the first three months of pregnancy) is thought to be 10 to 207. which is three to four times higher than the normal risk. Normally the risk of an anomaly is about 5%. However, if the exposure to German Measles occurs in the first four weeks it's chances of an anomaly increase to about 50%. If the exposure is in the second four weeks it's likely to be 25% of the babies who are affected, and in the third four weeks it is likely to be 16%. At the Heart Hospital they think the figure is much higher. I happened to have lunch with a couple of pediatricians from the Heart Hospital last week and they think on the basis of the babies they see, admitting that they have a special group, that the figure runs from 50 to 90% and they are in favor of sterilization or therapeutic abortion because of the risk. Even if the figure is 507., 507. of these babies will be normal and so there is a serious decision to make as to whether to destroy a baby because he has a 50% chance of having a defect, while at the same time you are destroying the other half who are perfectly normal. However, some effort is going to be made to change the law to permit therapeutic abortion under certain conditions and to let the family decide what course they are going to follow. There isn't any specific treatment for German Measles except gamma globulin which is available from the Red Cross and has to be used in large quantities (20 mm.) (which consists of ten vials), whereas a dose for a baby is 2 mm. or one vial. So you give this large dose and say that it probably won't do any good, but there isn't anything else to use. Some years ago when we had a lot on hand, we did give it for pregnancy. As soon as our supply was limited, we stopped giving it and were faced with the problem of telling the doctor that if we give this to his obstetric patient we will not have any for a baby who is exposed, who is ill and who may develop severe complications. We know that 2 mm- in a baby will effectively either prevent German Measles or modify it and prevent the complications. We have to give the pregnant women 10 vials for something that probably won't do any good. There have been some reports of value for the pregnant woman if the particular specimen of gamma globulin has a lot of anti-bodies, which means it must have been taken from somebody who was actually convalescent, but the Red Cross gamma globulin is not of that type. The general opinion is that it does very little good. Even though there are conflicting opinions and considerable doubt as to whether the gamma globulin will do any good, it is the only thing available and if it were my wife or my daughter I would want her to have it, even knowing full well that it probably wouldn't do any good. I would at

least feel I had used every method possible to prevent damage. Ordinary measles do not have the affect that German Measles have. Most adults ere actually immune, so there is little danger of the risk. Furthermore, there is now a vaccine available for measles and babies by the age of nine months should be given it as a routine prophylactic measure.

It is said that influenza causes an increase in anomalies, but I haven't seen any evidence of this. To play it safe, we advise that women, if they are pregnant, take a shot of flu vaccine. There are a variety of viruses and there are a lot of so called echo type viruses. I want to mention this one because the study that results in a negative finding may be just as useful as a positive one. In 1958, in the Twin Cities, we had an epidemic of virus infection due to echo virus type 9. There are about thirty types. We had 200,000 cases in the state and 20,000 cases in the Twin Cities. We thought this would give us an opportunity to study women who had been exposed to this particular type of virus and to see what happened to their babies. So we spent three month and we studied 10,000 live births in Minneapolis and St.Paul. We had nurses visiting all of the hospitals the day after the mother delivered. They got a history of any infection the mother had, with special reference to echo 9 virus infection. They got a sample of the cord blood of the baby at birth and put it in the deep freeze for studies of antibodies and then, because we only find half of the malformations at birth, we did a follow-up at nine to twelve months by telephone. That was quite an experience. We had to first figure out how long it was going to take to call women and talk to them and ask them how their baby is. We finally arrived at the five minute figure, with variation, ranging from three minutes to forty-five minutes. Our nurses called up 10,000 women to ask them how their babies were. Most of these women thought it was very nice of the Health Department to be so interested as to call up. There was another problem involved here. We had to eliminate all of the babies who had died in the meantime, because it would have been very embarrassing to call up a mother and ask about the baby and then find that the baby had died. We were quite successful. We only had one or two that we missed. As a result of this work and some six to seven thousand dollars, we found that there was absolutely no change in the number of malformations or mental retardation in babies born to mothers who were exposed to this type of virus. It is just as important to know this negative fact, so if a mother is exposed to echo type 9 virus, she can be told quite specifically that there is no evidence of any danger whatsoever.

In addition to viruses, there is a protozoan infection called toxoplasmosis. I hate to mention some of these things because the number of cases is so small that it seems silly. Actually, we have a record of 43 cases of congenital toxoplasmosis, but I number of these children are in institutions for mental retardation. This is

caused by ear excreta or direct contact with some animals or birds including dogs, cats, rodents, swine, sheep, cattle and chickens. The particular value of the diagnosis, however, is the fact that for some reason there is no danger of subsequent infection in subsequent pregnancies. We don't know why - we don't know what the transmission is, but in none of these cases has the mother had another baby become affected with this.

Then we have a large list of inborn errors of metabolism of which there are actually twenty identifiable amino acid disturbances, including the one commonly called PKU, Galactosemia, Histidinemia, maple syrup urine disease (because the urine smells like maple syrup), Hemocystinuria, and a lot of other fancy words, all of which constitute perhaps a dozen cases all told. As to Hemocystinuria, there are actually 30 mentally retarded children reported in the world from this condition and this is one of the 200 causes I mentioned. Another cause are vitamins and drugs. Dr. Cook, who is chief of pediatrics at Johns Hopkins University, was here about a month ago at a course we had for college instructors and he reported that he has found that women who have taken excessive amounts of vitamin D during their pregnancy have had babies who are mentally retarded. Since everything now has added vitamins, it's not very hard to get quite a dose. Excessive amounts of vitamin K given to mothers just before birth to prevent bleeding, have resulted in Erythroblastosis in a retarded baby. Long acting sulfonamides have caused kernicterus which is an RH problem with mental retardation. Just recently I read of a brand new syndrome reported to Harvard Medical School, a new previously undescribed syndrome involving marked accelerated growth,- non-progressive neurologic disorder with mental retardation, but no evidence of tumor of the pituitary of which five cases are reported. This just indicates the problem is getting worse, not better, insofar as diagnosis is concerned, since there is such a tremendous variety of conditions that will result in retardation in newborns and children.

Now with the premarital and the preconceptions! period, it is important that nutrition be stressed, particularly in the adolescent, because malnutrition in the pregnant woman leads to increased complications of pregnancy, particularly prematurity and toxemia.. Our school lunch program is a means of providing educational information both for boys and girls and it should be emphasized. One of the other things we have failed to do is to provide family life education for boys and girls. I shouldn't say we have failed to. About fifteen years ago we were in the business and it was called sex education then. We stayed in it for several years until we finally decided we had had enough and we quit because it is said that this is a responsibility of the home and nobody will dispute it. But parents in the homes are often not very competent in this area and so it sometimes becomes a church responsibility which a few churches have assumed. Since often neither one undertakes it, it

properly finally lands in the lap of the school because, if you can't do it anywhere else, the school is supposed to do it. Some schools have taken it on and have had problems. We even went so far as to publish a textbook for schools. The University wrote it and we paid for it. But it became such a hot subject that we finally quit it. The Child Welfare Institute is now offering lectures through the extension division, but I don't think they are extensive enough. It's a series of four lectures, two for students and two for parents and we have offered to subsidize it. Last year and the year before we had a series of four lectures each for students and parents and we would be glad to do it again, but with certain requirements. First the community must ask for it. We are not offering it. Secondly, the community must participate in it actively and one of the programs must be given by a panel from the community, including the clergyman, the physician, a parent and an attorney. Thirdly, they must have a financial interest in it. I don't care how much they put into it, but if they invest five dollars, its their program and they want to protect it. If we give it to them for nothing, it's worth exactly what they paid for it. We have paid too little attention to this area. These youngsters should know about growth and development and child care and illegitimacy with its progressive increase (for years we had an extremely low rate, less than 27., but we are now joining the rest of the states and our rate has gone up to 47.) should have some attention. Many of these problems are related to lack of information.

One of the sources of danger to young girls and pregnant women is x-ray exposure because of its genetic affect. We have a regulation requiring registration of all x-ray equipment of physicians, dentists, and hospitals. We have set up standards for ionizing radiation and provide consultation and assistance in the removal of any hazards. When we talk about x-ray exposure, we are faced with a problem if a particular patient needs an x-ray for diagnosis and treatment. Even if there is a genetic risk, we have to decide whether it is more important to treat the patient or whether it is more important to worry about genetics which may apply in subsequent generations. With the screening that is now possible in the use of x-rays, there is very little danger. Furthermore, I should call your attention to the fact that the cosmic rays to which we are exposed everyday from the air, water, and from bricks and rocks in homes, are greater and affect us more than all the radiation we could possibly be exposed to medically, so we don't have to worry too much about this.

Prenatal exams have been advised as a means of preventing certain congenital conditions, reducing mental retardation and syphilis. Some 37 states have laws requiring pre-marital examinations. Minnesota is one of the "backward" states that doesn't have it and here I'll quote Dr. Reed of the Dight Institute. At a

meeting of Nobel prize winners held at Gustavus Adolphus College, he was quoted BE having said this and pointing out that as a result of pre-marital examinations, we are able to find congenital syphilis and reduce its consequences which is true. He also said it would be possible to find a lot of unusual chromosomal diseases by pre-marital examinations and thus prevent the development of these things. I think this is a rather questionable remark for two reasons. One is, that as far as I know, anybody who is going to get married will pay little or no attention to any advice that says you shouldn't get married because love is not only blind, it is also deaf. Furthermore, the pre-marital examination doesn't include chromosomal examinations and isn't part of the routine examination. There aren't many places that could provide it. We are one of the few that could. Furthermore, as far as Minnesota is concerned, we have a case of congenital syphilis at least once in four years. I can't remember when we had the last one and that one was imported, not born here. While we recommend that Wassermann tests be part of all pre-marital examinations, we have suggested that they be given routinely only for first pregnancies. Subsequent pregnancies require having it repeated only if there is a new husband, the woman is widowed, divorced, over forty, or is non-white, because we have discovered no new case of syphilis by routine Wassermanns that we did not already know about before. We have no objection to having them done, - we do a quarter of a million a year - but they are not a very good source of case finding. It has been estimated that to find a case of syphilis by this method costs anywhere from \$5,000 to \$30,000 each and I think that's rather expensive case finding.

To come specifically to maternal and infant care, here the emphasis is on prenatal care. The Maternal Health Committee of the State Medical Association recommends that women be examined as soon as they know they are pregnant and that they visit the physician periodically. By this means it is possible to recognize early signs of impending complications by the blood pressure, edema, headache, albumin in urine, or bleeding and it's possible to recognize certain diseases such as syphilis and the problems of RH negative mothers. At Hennepin County General Hospital last year women who had no prenatal care ended up with 12% of the offspring resulting in fetal, deaths (babies dead before birth). In pregnant women who had one or more visits, the rate was 0.7%, so actually there was 5 times greater increase in fetal deaths with no prenatal care. This has been shown quite generally. I think it should also be pointed out , that prenatal care by itself, important as it is, is not going to protect against mental retardation. Prenatal care is essential and it will help reduce the number of complications, as well as possible mental retardation, but it does not prevent mental retardation simply as a prenatal procedure. The women who don't get prenatal care (and surprisingly enough, even women in the high income groups and with college educations frequently don't get prenatal care),

are mostly those in the low social economic levels who have to go to general hospitals or public clinics. They don't go because it is difficult to get to the clinic location, because of the eligibility rules, because of long waiting hours, and because they are treated in a rather impersonal attitude, which is perfectly true. This goes on at the general hospital. The services they get are excellent, the medical services can't be beaten. If I were in an automobile accident, that would be the place I would want to go; I think it's the best place in the state to care for traumatic injuries, and they have excellent services. They do have a very unfortunate environment in which to work. I think it should be pointed out too, that some of these women who do not get prenatal care for the alibi types of reasons I mentioned, probably wouldn't get prenatal care even if the clinic were next door, they probably wouldn't take the medicine you gave them unless you really poured it down their throats, and they probably wouldn't follow the diet unless you actually brought the food and fed them, because these women are what they are - this is the way they live. Included in the prenatal care are classes for expectant parents and this includes both husbands _____ and wives who want to know the anatomy and physiology, what happens and why and also to get exercises for so called painless child birth. One of the things that ought to be mentioned, even if gingerly, is family planning. Whether we like it or not, we are going to come to it and some health departments have set up health programs. At the last meeting of the Association of State and Territorial Health Officers they wrote a resolution saying that if any health department wants to undertake it, it would be a good program. I suspect that in the future there will be more and more done.

Now we come to obstetric care. The State Medical Association through its maternal health committee has prepared a guide, "Suggested Policies for Obstetric Care in Hospitals," for use in hospitals which advises on the types of care and the kinds of complications that ought to be handled with consultation in order to improve obstetric care and reduce cases of retardation due to anoxia and injuries of the brain during delivery. One of the important points in obstetric care is the early identification of women who have RH negative factors. If their baby is RH positive and they are RH negative, there is going to be a blood incompatibility and they are going to have erythroblastosis with possible brain damage from kernicterus. So the prenatal examination roust include testing for the RH factor and at the delivery they must be set up for prompt exchange transfusions. In RH incompatibility there is now a new approach. There have been a number of cases lately where the baby has been transfused within the uterus with good results, the number is small. It now has been done here in Minneapolis several times. By this means it will be possible to make a determination early of whether the baby is suffering damage, to exchange the blood so that this can reduce the rate and reduce the effects of the incompatibility. The other serious complication or serious condition which may lead to complication, is

premature birth or what is now termed "low birth weight infants." The mere fact that the baby is born early doesn't mean that it's premature, but what we are concerned about is the baby who weighs 5 1/2 pounds or less, in which case the rate of complication and damage to the baby is much higher; among the complications is mental retardation. Prematurity is increased in frequency in mothers under 20 or over 40, in first babies, multiple births, non-white mothers, those with low socio-economic status and those with dietary deficiencies. On the topic of smoking versus not-smoking, there have been some studies recently indicating that in women who smoke, the rate of prematurity is twice as great as in non-smokers. Years ago, before we knew the effects of smoking on the lungs and cancer conditions, I used to say, jokingly¹³ when they asked about smoking and nursing the baby, that the only thing they had to be careful about was not to get the ashes in the baby's eyes, but actually there is supposedly a greater potential risk for mothers who smoke. Acceptance of 5 pounds 8 ounces as the standard of prematurity, is a measurement that has been accepted because it is readily available. There are others that may be more valuable in accuracy, but they may not be as easy to get. X-ray of the ossification centers is not easy to get, and someone has to interpret it. The circumference of the head and chest is not easy to do while weight is easy to determine, so we have arbitrarily taken five pounds - eight ounces and this is accepted by all state health departments, the World Health Organization, and others. Birth weight is not always an accurate index of prematurity; you may have a baby that weighs five pounds, eight ounces, who is actually better developed than the baby that weighs six pounds or even seven pounds, this has happened. We have had some amusing situations with twins, where supposedly the older twin should weigh more, but actually weighs less, so we call the smaller baby premature and the baby of less gestation period the older one. This has happened a number of times. I've gotten letters from doctors asking me to explain it. The baby that weighs five pounds, eight ounces, but has nine months of gestation is called premature, whereas the one who weighs six pounds and has eight months of gestation is called full terms. Well, we have to have some standard and this is the easiest one since most people can use a scale and it's very accurate in contrast with trying to get the length of the baby or some other factor. There are a variety of factors associated with prematurity and these include multiple births, toxemia of pregnancy, bleeding, premature rupture of the membranes and syphilis, but in most cases from 35 to 65%, there is no known cause. The mother simply goes into labor early and delivers a small baby. It has been shown that small babies have more complications of various sorts and particularly neurologic abnormalities and cerebral damage, so that prematures are of concern. The longer a baby is able to be kept within its natural habitat, the more likely it is that the baby will be more normal and have less complications.

There is a direct relationship between the number of prenatal

visits and prematurity. There have been a variety of studies made. If the first prenatal visit occurs during the first three months, the prematurity rate in one hospital was 7.8; if in the second trimester, it was 8.7; and if there were no prenatal visits, the prematurity rate was 20%. The same thing is true in studies made at Hennepin County General Hospital. In Minnesota, our rate is 67., it has been for years, but in Minneapolis, the rate is 7% and this is because we have an increased number of women in low socio-economic situations and many who are not getting adequate prenatal care, so the prematurity rate is higher here. In the real low socio-economic tracts the rate runs from 11 to 19% in contrast to the 6% statewide. So you see, prenatal care, prevention of prematurity, and complications of pregnancy are important factors in the reduction of handicapping conditions, and particularly mental retardation. Among the services of the Section on Maternal and Child Health are a variety of programs that have to do with this. I made clear at the beginning that in Minnesota the State Health Department runs no medical, clinics of any sort, provides no medical or hospital care; our program is entirely educational and consultative. We do not provide any direct services. The only exception to that was during the war when we ran the so-called EMIC (Emergency Maternal and Infant Care)¹ program for wives of soldiers. Other than that we do not run any. There are clinics in the Twin Cities, Duluth and Rochester that are run locally by local health departments. We have no objection to clinics, providing somebody else runs them. When groups like the Legion Auxiliary or other organizations want to set up a clinic, we tell them we will be very happy to help them set it up, providing they have the approval of their local medical society. To my knowledge, in twenty years, I've never seen them get this approval, so it's quite safe. Since we don't run the clinics ourselves and since we don't have the staff to run them, they have to be run locally by local physicians, and if local physicians don't want to operate them, they are not going to be operated.

The prevention of prenatal and neonatal defects and abnormalities during the first 28 days of life with resulting brain damage requires that all newborns have an examination promptly - an observation both by physicians and nurses to discover any brain damage, any evidence of malformation or any genetic affects. Many of these babies are not examined. In reading hospital records, frequently only the nurses notes tell us anything. Apparently quite frequently physicians don't even look at babies. Maybe they don't like babies! In the post-natal period after birth, proper feeding and treatment of infections and immunizations are important. The question of physical trauma is particularly important because head trauma due to auto accidents or head trauma from the "battered child's syndrome" may lead to retardation. Are you people familiar with the "battered child's syndrome?" That's one of the popular things now. Strange as it may seem, mothers and fathers do sometimes beat their children, breaking arms and legs, actually causing

brain damage and children have died from this. It's a difficult thing to spot because they don't go to the same hospital twice. But if the doctor looks at the child's x-rays and finds that the child has had previous fractures, it should be suspected. It has become so prevalent that many states have passed laws, including Minnesota, which passed the law two years ago. But unfortunately the law is attached to the law relating to gunshot wounds which says that any doctor that sees a patient with a gunshot wound is supposed to report it to the police department. There is an additional clause that says that any children suspected of having been maltreated by their parents are also supposed to be reported. Few physicians are reporting, however, and some physicians have suggested that they prefer to report to welfare departments. That's a switch, because physicians in general have had less use for welfare departments. Morris Hirsch, State Welfare Commissioner, was very elated when he heard that doctors did prefer to report to him rather than to the police department. The difficulty in the department of welfare is that welfare is on a forty hour week, whereas the police department supposedly runs 24 hours per day. There is going to be a suggested change in the law to include welfare because actually it doesn't make much difference whether you report at 3 A.M. or 8 the next morning. There have been more and more cases of this sort and when the -youngsters have been examined thoroughly, it has not been found infrequently that they were victims of maltreatment by their parents.

On the birth certificate we have a confidential medical section, that physicians don't like, which asks for data on various complications of pregnancy, RH factor, birth injuries and congenital malformations. It is used as a case finding medium. There is a new question there, the date of marriage which may not coincide with the date of birth of the baby. We added this section to the birth certificate because we have very good information on maternal deaths, because we have a maternal mortality study which follows up every death. The total last year of deaths due to obstetrics actually totalled eight. The number of cases studied by the committee totalled 35. Because this regulation states that any death of a mother as a result of pregnancy or within 90 days postpartum after the birth of a baby, regardless of the cause of death, is included in the study. We have the peculiar situation of a mother having a perfectly normal delivery, but two months and twenty-nine days later having been hit by a streetcar and automatically falling into the study. The reason for including them is that many of these women died from conditions related to the pregnancy, but it did not appear on the death certificate as such. So we have included everything within 90 days. We are interested in the care during the prenatal period and the obstetric period, even though we are not particularly concerned with the actual cause of death. So that we have accurate information on it, an obstetrician actually visits the physician and hospital. We do not, however, have any information on morbidity.

The mother may have had very poor obstetric care and still survived with some complications that will stay with her the rest of her life, but we have no information on it. We added this form two years ago so we would have some information specifically on the relationship of age at marriage and education to certain complications and would be able to obtain information on congenital malformations periodically, so that we could discover any increased incidence in any type of malformation and follow it up. Most physicians have been filling it out, some have been filling it out poorly. Where the hospital librarian has done the filling out, we have gotten a very good report. Recently we changed the form to add a few questions and some people are protesting that it is too long. It is a long form, but in order to make it simple, we have places where it can just be checked. We even broke down the congenital malformations into specific causes to permit a check mark instead of writing it in, but some physicians have objected to this. When we first started it, it had a confidential section. Incidentally, all of the studies done by the Health Department, either alone or in cooperation with other agencies, are protected by the so-called Confidentiality Law. This makes all of our reports and records confidential. They cannot be used in court, so the physician doesn't have much of an argument in saying this is confidential information which he shouldn't release. It cannot be subpoenaed. In Minnesota, unfortunately we do not have full time health departments except in four places. This means that these certificates are filed not with the Health Department, but in most cases with the clerk of district court. The doctors are worried that the clerk of the district court, having nothing to do, will sit down and read these things and know more about his neighbors. When we made this revision, which included half a dozen more questions, we also passed a regulation which has the same affect as the law and has been approved by the attorney general and now is in effect. The law says that the attendant will not only fill out the birth certificate, but will also fill out the confidential section. As a result of these, when we tabulate data we will be able to cross tabulate them and determine that women, say at the age of 17 who have had two babies, are more likely or less likely to have had this or that complication or to have had this kind of malformation. This procedure costs about \$5,000 to put on punch cards and analyze. The fact of the matter is that this is the only way we are going to have state wide information available on something that we ought to know about. Most of the physicians actually do cooperate. With this information available, we are now going to be able to provide the crippled children's services with a list of babies with malformations which are correctable, such as cleft lip and palate, congenital heart or supernumerary fingers or other things, so that they will be able to check with the physician to see if the babies are under care. If they are not under care, they can check with the family and let them know that there are services available for the baby, even though the families themselves cannot provide them.

The other method of getting information, which has not worked so

well, is the annual school census. This is required by law for all children under the age of 21, from zero to 21. Every year every school district is required by law to make a census of all their children in their school district and list those who have defects, for which they get \$10.00 per name. Since there are no rules or regulations as to how this shall be done, the method of doing this varies. If the census taker is paid so much per name and the object is to see how many names you can get, there will be less concern about the accuracy of the information. If the census taker is paid so much per day or per hour, they probably will not hurry about it. There is no set rule. The other problem we run into is that the form the census taker fills out does not provide the information we want. This is understandable when we note that the people who do the census may be anyone - from a school teacher who is not working to a nurse who may get more adequate data, to a janitor or to anyone else who has a friend on the School Board and needs a job for a couple of months. In order to standardize it, we had a sociological study made. We had a couple of sociologists visit a number of schools, set up a training program and devise a new form which was to solve the problem. We have not yet been able to induce the State Board of Education to make it compulsory - this is the first requisite - that a certain form be used which would be of some use to us. I understand that some people have looked at it and think that the form that was devised ought to be revised before it is used. We did spend some \$4,000 on the study. However, if these forms were filled out properly, they would give both the Department of Education and the Department of Welfare some information on the number of handicapped children of various types and their ages and would give some information as to what services they ought to plan. The argument of Welfare and Education is that they don't know who's coming to school until they actually arrive because the school is not responsible until the child is five years old. This way they would know within a couple of months after birth what these conditions are and the school could be alerted to the fact that they are going to need to have provision of special services for certain handicapping conditions. In theory, this is a wonderful way of getting information to them; in practice, it hasn't worked so well.

One of the means of using statistics for research as a means of reducing mortality is analysis of the perinatal mortality records, that's the baby's fetal death certificate, including those who are born dead and those who are born alive but died within the first 28 days. It may seem strange that I don't say 30 days; it is actually 28 days and we have gone through our records and apparently no babies die on the 29th and 30th day, believe it or not - they all occur actually within the first 28 days. The American Medical Association has a study along with the College of Obstetrics and Gynecology and the American Academy of Pediatrics in which they are analyzing the statistics on these babies in 400 hospitals in the United States, ten of which are in Minnesota, As a result of that study we are

going to have information on the various complications and causes of death - particularly malformation. In Minnesota we have had a study in Hennepin and Ramsey Counties and one in Duluth for several years, in which we are concerned with the correctness of the cause of death, the adequacy of the medical and hospital records, adequacy of consultations and any errors of omission or commission. Each report enumerates the various preventable factors and is used as an educational program as a means of reducing infant mortality.

Another situation with which we are concerned and which has to do with babies is accident prevention. Accidents are the leading causes of death in children up to age 19 - in fact up to the age 35. There are more deaths from accidents in children than the leading six causes of death from disease. In addition to causing death, brain injuries due to head trauma from automobile accidents, falls, and blows may, of course, lead to mental retardation.

We are concerned with school health services in the field of mental retardation because hearing loss and speech handicaps may be the cause of retardation rather than the other way around, so that these children should have adequate screening and follow up. We provide consultants in hearing and vision and assist schools in in-service training of volunteers for screening, and we are including pre-school children as well. There are three general approaches in public health - education, prevention, and medical care. Actually in Minnesota we limit ourselves mostly to prevention and education. We do not provide medical care, we do not pay for hospital or medical services, or dental services, but we are concerned with medical care because we do license hospitals and we set standards for them, minimal as they are; we provide consultants in maternal and child health to hospitals and we do provide genetic counseling, so that we do have a direct interest. With the new federal programs that are coming, we may be involved in direct medical care, much as we would rather not be. With 99.77% of all babies being born in hospitals, the hospital licensing becomes a major responsibility. Unfortunately we have only one set of regulations for all hospitals, whether they have ten beds or 800 beds, so we have no way to differentiate between a small hospital and a large hospital. This is why our regulations actually are as minimal as they are, because they have to be minimal enough so that a small hospital can meet them. Therefore, they are so minimal that most larger hospitals and twin city hospitals exceed them. We have at the bottom of each page recommendations for larger hospitals, but these are not regulations and we cannot enforce them. However, most hospitals are providing adequate service and most of them have modern equipment now. We provide maternal and child health nursing consultants who assist in developing standards for hospitals and who provide consultation to hospital problems, particularly consultation of maternity and newborn problems. We provide in-service training for nurses in workshops; we have a three week course for maternity nurses and one on

premature care, as well as classes for parents. We do not have a premature center in Minnesota, as a few states have, because all the general hospitals in the Twin Cities have maternity services and have adequate care. We are still going to have that babies' hospital built, but it is not going to be taking care of prematures. We would prefer to have the babies taken care of near home in a hospital large enough to have trained personnel where care can be rendered. If you have a central hospital, the babies have to be transported long distances and the statistics I've seen have to go to the third decimal point to prove that the \$2000 to \$3000 that it costs to keep a baby in such a center has changed the mortality very much. In order that small hospitals may have people who have some training, we are providing courses in two hospitals in Minneapolis and St. Paul where they have a three weeks course in practical care of the premature and maternity care; we pay for their living expenses and their tuition. The hospital has to agree to carry the nurse on their payroll and find a substitute in her absence, so this girl goes back with at least some practical experience in specialized care. We also provide a consultant in obstetric anesthesia and she is concerned with obstetrics and anesthesia in maternity patients as well as in care of the newborn. We have a human genetics unit which was established three or four years ago, where genetic counseling is available to physicians, hospitals, adoption agencies, welfare departments and where there is maintained a register of genetic and congenital diseases, including mental retardation, PKU, RH factor babies, twins, congenital malformations and birth injuries. We have recently established a human cyto genetics laboratory where chromosome analysis for diagnosis and counseling will be possible. There are about 56 youngsters with PKU at Faribault and about 37 have been seen here by the University. We are conducting a study with the Department of Welfare and the Faribault State School in following up the families and siblings of all these youngsters to find the carriers in the family. When we determine the distribution of these carriers we will alert the families to possible recurrences in the future offspring and will provide genetic counseling to them.

What I'm about to say now is going to be very complimentary as to what nurses can and should do; I'm not saying they do do it, but this is what they're in a position to do in the field of mental . retardation, if they wish. One important function, if a nurse is doing any prenatal work, if she is seeing women early in pregnancy, she is in a position to find those women who have a history of difficulty in previous pregnancies and are, therefore, high risk women who should have prompt and early medical supervision. She is in a position to educate adolescent girls, especially in pregnancy, to the importance of nutrition and the prevention of complications of pregnancy, so they will understand nutritional needs and cultivate desirable food habits. She can screen babies by doing a blood screening for PKU. She is in a position to find retarded children through her daily activities, through home visits, school visits, and child

health conferences. She is able to recognize consistently slow growth in children, slow motor development, inadequate self care, problems of language, expression, comprehension and disturbances of behavior and attention. She is able to assist in stimulating classes for the retarded as well as for other physically handicapped children. She can stimulate safety programs and practices in the home, in the school and in the community. And if safety seems to be out of place, just let me mention a few examples of a direct relationship. I have already mentioned brain injuries. The receiving of penetrating bone injuries or head injuries, traffic accidents or falls or playing with scissors can bring about brain injury which will either result in death or brain damage with probable retardation. Toxic exposure to lead causes mental retardation. In Minnesota we have very little of it, but in older cities like Baltimore, St. Louis or Chicago, where there are a lot of old houses in the low socioeconomic areas where lead paint has been used or where cribs and furniture may be painted with lead paint, youngsters eat flakes of paint and develop lead poisoning. Anocia can

be caused by carbon monoxide inhalation from invented space heaters or from cars that are left running with the garage doors closed.

This leads to brain damage and death as demonstrated by a couple of our University students recently who had their motor running with their car doors and windows apparently closed. We have suffocation from discarded iceboxes and from plastic bags that can lead to mental retardation - if not death.

Since this is getting too serious, let me tell you about a legislative action which I found very amusing. A number of years ago the legislature was in session, at a time when there were a number of cases of suffocation in the east when youngsters became locked in iceboxes. We had had no cases in Minnesota of that sort but we had a lot of cases of poisoning. Two bills were introduced in the legislature; one said that all discarded iceboxes had to have their doors or hinges removed and the other said that all toxic substances and drugs had to have a skull and crossbones on the container and a label that said it was poisonous. The bill relating to discarded iceboxes, from which nobody here had died until then, passed, but the one relating to the labeling of poisonous substances, from which we had had a number of deaths, did not. This is simply a matter of interpersonal relationships; who cares about discarded iceboxes, but there are vested interests in drugs and chemicals because someone might not buy something with a toxic label on it. Since the law passed we have had a number of suffocations. I don't blame it on the law but this is the way it happened!

Many children should be referred for early immunization, particularly for measles and whooping cough, because these diseases frequently cause encephalitis with consequent brain damage and retardation. Tuberculin testing should be done for possible tuberculosis, because it is important not only to diagnose the case and to

discover the exposures, but also because tuberculous meningitis which occurs in children can result in brain damage. In PKU, the nurse is in a position to assist the family in translating the recommendations of the physician into effective management of the child and proper diet. She can advise on feeding problems and reinforce the teaching of the nature of the disease. She can interpret hereditary effects and she may assist the family to integrate the PKU child into the usual pattern of living.

By law, all problems related to retarded children belong to the State Department of Welfare, the county welfare boards and to the State Department of Education: We have absolutely no authority in it. The Department of Welfare is responsible for mental institutions, mental retardation institutions, mental health agencies, crippled children's services, Gillette Hospital, day care centers and is designated the official mental health authority by the governor. However, the public health nurse in health departments and county nursing services probably knows more retarded children and has more contact with them than anybody else. This is why we are in the business.

Now let me briefly review the federal agencies' concern with mental retardation and where we get our money. In the Department of Health, Education and Welfare, the public health service is concerned with specific grants, runs the National Institutes of Health, one of which is the National Institute of Neurological Disease and Blindness. This Institute is carrying on a collaborative prenatal project, studying cerebral palsy, mental retardation and congenital malformations. It is being carried on in fifteen medical centers, including Minnesota, on 50,000 randomly selected pregnant women and their newborn. There are now 36,000 in the study. To date they have found that one out of sixteen babies born had some neurological or sensory defect. They also found, as far as birth defects are concerned, from blood serum findings of these women, many whom thought they were immune because they once had German Measles, nevertheless they had hidden susceptibility. They also have worked with scientists in finding the specific cause of German Measles and by finding the virus of German Measles, they are now working on a vaccine, so the answer may soon be a vaccine for children. One of the newest institutes is one on Child Health and Human Development where studies of fetal neonatal, infant and child development are going on. There is a research and training program on mental retardation and research in other aspects of human development. I understand in addition to infant-child development, aging is also part of the program. I attended one meeting in Washington and was surprised to find the head of the Child Welfare Institute also interested in aging. I was told that research on children was now moving over to research at the other end of the scale, research on aging.

The new branch we have now is called the Mental Retardation

Branch of the Division of Chronic Diseases, so we now have several different groups which have money to spend on mental retardation. They are concerned with a variety of duties. They administer the mental retardation planning grants which all states have gotten for comprehensive planning and construction of community facilities.

There are two programs I want to mention specifically that are in the Health Department. These are two Four-County Projects for retarded children. The first one was established in Fergus Falls in 1959. This was a result of a special grant of a million dollars that Congress made available to the Children's Bureau at the behest of the parents' association. The money was given to the Children's Bureau to set up diagnostic centers, practically all of which are associated with medical schools or universities. The only exception has been the one in Minnesota which is not associated with the Medical School and which is in the Health Department because that is where the Maternal and Health program is. It is in an isolated area 200 miles from the Twin Cities, because the project was originally ~~set up by welfare. Starting out with a request for \$17,000, it ended up at \$60,000. The objective was to find all of the~~ ~~off the retarded~~ children under 21 in the four county area, to provide a complete evaluation by pediatric examination, ~~laboratory work, psychological~~ testing, social service work, counseling and helping the child receive whatever services could be of benefit to him, which in most cases was educational services. As a byproduct, the community was taught the needs of these children, and as a result of that, there are a lot more services for these youngsters than there are in most areas, including a sheltered workshop. There has, however, been a serious problem of staffing, because there is a mental health center in the town which has no restriction on salaries, whereas we are restricted to the civil service salaries. Consequently, the last ~~three~~ psychologists we have employed, have been lost to the mental health center at higher salaries. During the eight years of this center, 1346 children were referred, of whom 743 were accepted for service and 344 for follow up evaluations. About half have actually been retarded. The presence of this project has stimulated a total of 24 formal school programs during this period. A sheltered workshop for vocational training has been established. We are now proposing to turn this over to the mental health center where adequate staff is available and pay them for complete services at a flat rate per child. There would be a fixed amount for total services for a new child and a lesser amount for subsequent services after the first year when they don't need the extensive examinations. This is quite a shock to the Children's Bureau because it is heresay and represents an entirely new approach. Since they are competing with the Public Health Service, they want to be able to point to the clinic that they are subsidizing to the extent of \$60,000. If we put it into the mental health center, it may lose its identity and be submerged by mental health activities with little consideration

for mental retardation. Consideration is at least being given to this suggested change in providing adequate services.

In the meantime, the Children's Bureau obtained more money and I was invited to have a second diagnostic center. This time I thought I would select one close enough to the Twin Cities so that I would have less trouble staffing it. The new one at Owatonna is only 60 miles from town, but even so, we haven't been able to staff it. We have a pediatrician part time, which is sufficient, but we do not have a psychologist because we happen to be in the same building with the mental health center and if we got a psychologist, he would only have to walk down the stairs to earn \$2,000 more than we are offering. This is the situation we are in. Until we can get a salary scale that competes with the mental health centers, we are going to have problems. On the other hand, one of the objectives this second center has written into it, is to demonstrate that it's possible to provide all of the services that we are now providing at a cost of \$60,000, as part of the on-going mental health centers, of which ~~there are some 20 or 22 in the state of Minnesota, without setting up a separate center. So in these two places, there are services~~ available for children if there is staffing available. We would now, to have the mental ~~prefer, under the program we are writing u~~^{up now,} health centers take over the functions of these specialized diagnostic centers. Unfortunately, in Minnesota these centers receive 50% of their money from financing through the state, but there are fewer restrictions on them. Each center is independent and can do pretty much as it pleases, so each center may have an entirely different program, depending on the interests of the program director, the psychiatrist, and the psychologist. Until they convince the centers that this is a necessary function, there is not going to be adequate service.

The chief money up to now has come from the National Institutes of Mental Health and until recently, mental retardation was a step-child, not much recognized by psychiatrists. So psychologists got into the act and have been more active in the field than have the psychiatrists. Mental health funds were not used to any great extent for the retarded and parents' associations are a little hesitant about having the two join together, because they are afraid that mental retardation will be lost in the shuffle. In Minnesota, the association has agreed to go along with the idea, although I think nationally they are a little skeptical because in the past, the experience has not been to the benefit of the retarded. Most of the money has gone for mental health and mental disease, not retardation. Here in Minnesota we are going to try to put them together, but how successful it will be will depend on the individual centers, their attitudes and how well they are going to work together.

There is money available for building facilities for both mental health and mental retardation. Minnesota has not gotten any money

yet because we have not written up the state plan. There are a number of organizations that have asked for funds to build centers. The center at Fergus Falls is going to build next door to the hospital there. This is the pattern we would like to see develop, of having a center in close connection with community hospitals, so that there will be adequate staff available as well as medical services, hospital services, and out-patient services.

There are monies available in the so called Anti-Poverty program, which is supposed to include children from families with incomes of less than \$3,000, preschool children who are culturally deprived or have siblings that are retarded or have other handicapping conditions. These youngsters are supposed to receive education, medical and health services, so that when they enter school in the fall, they will be better able to compete with so called normal children. Minnesota has such a project for some 800 youngsters; they are getting \$72,000 of which less \$6,000 is for medical and health services. This is supposed to pay for an examination of each child, for visual and hearing screening and a few other things. They had a request for medical care in the budget, but this was not approved, I suppose on the theory that these families are eligible for General Hospital care and could get medical services there. There is money in it to hire physicians part time to run some clinics for examinations, but there was no money in it for dentists. The dental society has agreed to provide services, but when they discover that the doctors are going to be paid and the dentists are not going to be paid, I think there may be a slight problem. Since the program has to be run in an area where health, education and medical services are available, there will probably be some counties that will want this service, but they will have to be limited to families of low income.

The other program is the maternal and infant care program, which is available with lots of money to provide prenatal care as well as complete obstetric care for mothers. Originally the law said it was for mothers who were likely to give birth to retarded children. Somebody finally woke up to the fact that it is a little difficult to pick out the mothers who are going to have retarded children, so it has now been changed to mothers of high risk and they have listed a variety of things that come under the high risk category. Minneapolis has such a program. They have a grant for about \$100,000 which will provide three clinics in operation other than the one at the University. It cannot be city wide. It has to be restricted to neighborhoods which have a low socioeconomic level, increased infant and neonatal mortality, increased birth rate, increased prematurity and other factors of that sort. The three clinics started in operation about the first of the year; they have seen about ninety patients now. They can pay for prenatal care for anyone that walks in. But when it comes to obstetric care, it has to be someone that qualifies. If you end up with a normal

baby, you have done a pretty good job, so that the definition is not too severe. You only have to suspect the high risks. A history of previous miscarriages or previous difficulty with labor complications or previous handicapping conditions makes a woman a high risk mother who is entitled to service. We run into one complication, however, in that the General Hospital provides obstetric service to anybody that walks in. Any mother can come in and if delivery is imminent, she will get obstetric care no matter who she is or what her standing is. Under this new system, they are refusing to give this care except to those who qualify and since they are getting prenatal care, they now know their status and they will be classified either as "eligible" or "not eligible." The other thing is that while they are supposed to have free choice of hospitals, they are not getting it because they now want them to go to General unless the woman insists otherwise. The care at General is first class, but the prenatal care is less than adequate because of their environmental facilities.

Women who are eligible under this program can have their prenatal care there, but when it comes to the obstetric care, they either have to qualify specifically because they have some condition which makes them appear to be a high risk patient or they must be eligible for General Hospital because of their income. The high risk patient is defined by criteria which includes these: toxemia of pregnancy, hemorrhage, dystosia or difficult labor, medical condition such as anemia, malnutrition, hypertension, infection, RH incompatibility, multiple pregnancy, threatened premature labor, pregnancy in women under 16 and over 40, a history of premature birth, miscarriage or other perinatal casualties, a history of previous birth of cerebral palsy, metabolic disorders and out of wedlock pregnancy.

St. Paul has written a provisional plan for setting up something there, but they have not yet decided exactly what they want. One of the problems we have had with prenatal care is that some mothers do not go, even if the clinic is right across the street. Under this program, you can pay for a taxi to bring them there, you can pay for baby sitters to stay with other children, almost anything to get them there to take the service. They do have well baby clinics in St. Paul at some of the housing developments and a well baby clinic can be changed to a prenatal clinic by the addition of an obstetrician for a couple of hours. The purpose, of course, is to discover these patients early and to reduce the incidence of handicaps, if possible, and if we cannot reduce the incidence, at least to provide them with early care.

One of the programs we established as a result of the increase in funds is the PKU screening program for newborns. I understand from recent developments that there is going to be a bill in the legislature to make PKU testing mandatory. We started doing screening three or four years ago with ferric chloride. Then two years ago when the Guthrie field trials were carried on, 32 state health

departments participated with some 600 hospitals. They did 10,900 screenings and found one positive case. The figure of one case of PKU for 20 to 30,000 births is not correct. In most places they now find it closer to one per 10,000. As of August, 1964 we started the statewide Guthrie screening on a voluntary basis and we provide the filter paper on which three drops of blood must be placed, mailing envelopes and information to all hospitals. We have a public health nurse who is going to do the follow up. We furnish nutrition consultation and human genetics counseling and we are now running about 200 tests a day. Up to January 1, 1965, we had run about 15,000 tests. We have found one positive case in a five weeks old baby and one in a three year old. However, this is expensive case finding. At one of our board meetings, a board member wanted to know what does it cost to screen a baby. I told him it is said to cost 50 cents, but I would suspect it costs closer to a dollar, including the follow up. He inquired if \$10,000 wasn't rather expensive case finding. And didn't I think the money could be used to better advantage some other way. I pointed out that this money that comes to us has a label on it, "Mental Retardation," so there is no real choice of whether we think other things are equally important. From the standpoint of a baby, the fact that he is not going to spend fifty years in an institution, this is cheap case finding. One hundred fifty two out of one hundred seventy hospitals in Minnesota are now doing PKU testing. Six of them in Minneapolis are doing it only at the specific request of the physician. One hospital refuses to do it entirely. They don't think the test is good enough. As soon as they have a baby with PKU that is not diagnosed, then we will have services at all hospitals. There may be some advantage in having a law on the subject, but I am inclined to think a voluntary approach is sufficient. In some states where it is mandatory, they are getting no better results than we are getting on a voluntary basis. One proposed law actually states that they shall do Guthrie testing. This is ridiculous, because if a better test comes along, as it will, they will have to wait until the legislature meets again in order to change the law. We suggested that the law should say that physicians and hospital administrators would have to see to it that the baby was tested promptly and that the type of test, the reporting and the follow up would be as prescribed by the State Health Department. We could then write regulations which could be changed as the need arose. We are hoping that this is what will be done.

Let me mention briefly coordination and cooperation in this state. There is an interagency committee on retardation of the Departments of Health, Education and Welfare, which includes the Executive Secretary of the Association for Retarded Children, county nurse, a welfare executive and an official from one of the state institutions on the committee which meets every couple of months to exchange information and to coordinate activities. There is the Governor's Council on Children and Youth and the Governor's

Interdepartmental Committee, on Children and Youth. We have an advisory board on handicapped, gifted and exceptional children, which I mentioned previously and then there is the Governor's Mental Retardation Planning Council which received the grant I mentioned. This includes the State Department of Welfare, employment security, health, corrections, education and the Association for Retarded Children and the chairman of the Advisory Board of Handicapped, Gifted and Exceptional Children. This group has set up ten task forces and is developing a state plan. I hope we will be able to get it out this year.

Shall I tell you what's important? PKU has to be important because there's all that money floating around for it and we assume it has to be important because of the money. The fact that it can be recognized early and there is a treatment available to prevent it from becoming aggravated is of importance. Secondly, I would stress the importance of adequate prenatal care for all mothers and particularly for mothers of high risk, who have had a handicapped child or has had complications. Thirdly, since I am now concerned with it, I would stress the importance of providing young people with adequate education so that they know what life is going to be like, that there are problems involved and they ought to know something about family life, its problems and its complications. Fourthly, that there will be continuing emphasis on genetics which has been recognized as significant and there will be an expansion of genetic counseling and genetic services.

RESEARCH AND DEMONSTRATION PROJECTS

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As an introduction I am going to talk with you informally about research and demonstration projects and their place in the total movement in the field of mental retardation.

Let us talk first about research. My purpose is not to review specific research but rather to talk about the place of research as a general activity. Some time will be given to a discussion of specific research problems, but only as illustrations, or a way of clarifying some point in my general presentation. Research is comprised of a wide range of activities. Always it is concerned with finding clear and useful ways of viewing problems. Usually it involves collecting evidence of some sort. Research may be initiated because you wish to make a certain type of decision more efficiently or accurately. Or, you may be testing out an idea which you believe will improve some treatment program.

In my view, every teacher in every classroom, who has an idea and who tries it with, "Johnny" or "Mary" and who makes some evaluation of the idea to see whether there is improvement, is involved in research. Every psychologist who is thinking and experimenting as he gives his tests and who makes predictions and checks them is engaged in a kind of research. Through such processes the psychologist and the teacher make themselves into more useful instruments. So, in what I am calling research we include a broad range of things, all the way from the informal kind of activity which the teacher engages in day-by-day to the highly rigorous kind of quantitative research undertaken by the experimenter. Research is not undertaken only in laboratories; it goes on whenever and wherever there is serious inquiry concerning better ways of thinking about problems and better ways of dealing with them.

It is important that all of us, whether we are involved in highly rigorous research or in some very practical job, feel we are a part of this adventure of "making inquiry" in our field. Secretary Wirtz of the U.S. Department of Labor, in an address in this community just a week ago, said that, "We, more than any other people at any other time, are inventing our own future." This is certainly true in the field of mental retardation. We are investing heavily in research through a variety of forms in an attempt to improve the future of retarded individuals.

The present fact is that in the field of mental retardation, most aspects of our programs are based on weak evidence. It is very

important that we extend and improve the fund of knowledge from which we draw in designing programs for the retarded. It is important that we utilize fully and rapidly all research findings which are developed.

How let's spend a bit of time breaking down this matter of research. We can analyze this total complex so as to see its many parts in a number of ways. For example, we might make a distinction according to methods applied in research. A list of different methods might include the following: experimental research, correlational research, survey research, and historical research. Let us look briefly at each of these.

By experimental research we have in mind studies in which systematic efforts are made to manipulate behavior or other variables. There is definite experimentation. The experimenter try's to influence a variable to see what effect this has. Experimentation involves a comparison with so called control groups in which you do not manipulate the variable. You hope that experimental and control groups are equated on all things other than your experimental variable. This may be done by statistical means or by matching of subjects or by some other means. You then try to estimate the effect of the experimental variable and assess it statistically to see if the thing you believe makes a difference actually does make a difference. Experimental research has high prestige. It is the kind of research for which money is most readily available.

Let us look quickly at survey research. In recent months we have been concerned in Minnesota about the adequacy of staffing in our institutions for the retarded. One can study the ratio of staff to patients in institutions. A survey on this item might extend across the country to include all institutions for the retarded. Then we would have a basis for comparing our Minnesota situation with the national "ratios." A few years ago I had reason to look up results of such a survey conducted and published by the National Institute of Mental Health.

I think it is clear that in so-called survey research you simply seek information which will be useful in planning or in decision making; you are not attempting immediately to influence anything, nor are you attempting any fundamental inquiry as to "what causes what." Surveys can be made on almost any topic. Results are often useful, but this is not considered to be a very fundamental kind of effort in the whole galaxy of research endeavors.

Let us consider the correlational research. Here our concern is to discover correlations among variables. We are asking questions about real situations but we are not trying to influence anything. We might ask: is there a tendency for communities which have fully developed special education programs to send fewer

youngsters to state institutions for the retarded than communities which do not have special education programs? We could make a study of this, as indeed we have, to see whether there is a correlation between institutional referral rate and the adequacy of local special education services. Or, we might do studies to find what variables predict successful release from institutional placement. In such research there is no attempt to change anything. We simply study relationships or correlations.

Obviously, correlational research is not fully satisfactory in most situations. Mere prediction is quite hollow, but it may give some clues as to points at which interventions would be possible and fruitful.

Another category of research according to classification by methodology would be historical research. Just a few days ago I reviewed a proposal for a research project developed by one of my colleagues at the University of Minnesota. He proposed a very large study of immigrant groups in this country covering the beginning parts of this century. His belief is that if a careful study of immigrant groups were made, involving substantial knowledge of the background of groups, along with the information on the problems they encountered in this country, it might be possible to sort out the ways by which some of them successfully managed for themselves in their new homeland. The research might produce insights useful in dealing with subgroups within our population which are yet alienated or disaffiliated. His hope is to find ways of understanding how people become fully affiliated and successful in a complex new culture. Obviously, this study is not immediately concerned with mental retardation. On the other hand it might produce findings which would be useful to those of us who work in the field of mental retardation.

So far we have touched briefly upon a variety of approaches to research according to differences in methodology. Research may also be classified in a number of other ways. Sometimes a distinction is made between what is called basic research and applied research. Many speeches are given urging more support for "basic" research. This is research that has no immediate applications but where the researcher is simply trying to understand the variables that interrelate or what factors have what effects. The researcher, as such, is not interested in any particular form of application and indeed may know very little about applied work. An example which comes to mind is some research developed out of a theory by Rotter which suggests that mentally retarded individuals tend to be more "outer directed" than "inner directed." Involved is a concept of "locus of control." The theory proposes that in normal child development there is a tendency for children to become more internal in their locus of control. That is, they become more ego involved in behavior, and they see themselves more responsible for success and

failure of events as compared with the immature tendency to attribute cause to forces external to themselves. Development of internal locus of control is said to be more correlated with mental age than with chronological age, and so those who are low in mental ability would be expected to have a special problem in developing internal locus of control.

My point for present purposes is that some of the studies are not particularly concerned about whether the retarded ought to be "internal" or "external" in locus of control or how you would go about influencing an individual's "locus of control." Others who are more applied in their orientation may come along and find this research to be useful in explaining practical behavior in retarded children. And eventually it may form part of the background for new teaching techniques.

There is quite a lot of talk today about translating basic research into applied research. And I think this is meaningful. There are some people who attempt to stay in touch both with basic research and with applied situations. I am in the field of educational psychology and I expect that one could define educational psychology in terms of translational role it plays between basic psychology or academic psychology and education.

One may also classify research according to content or substance or area of concern in the field of mental retardation. For example, we often speak of bio-medical research, behavioral research and educational research, etc. The reports of the President's Panel on Mental Retardation were separated in terms of these kinds of content differentiations.

A number of other approaches to research classification might be made. Indeed, the "types" of research are almost limitless. But what I have said may be sufficient to establish that research is greatly various in method, content and purpose.

Let us now shift our attention to demonstration projects. Two main categories or approaches may be identified here, both of them concerned with using demonstration methods to disseminate knowledge. First, there are projects which represent a transition from research to demonstration. When research has led to a discovery which ought to be communicated to other specific groups of people, you may choose to handle the communication through a demonstration project. You design an outstanding illustration of your findings, along with good provision for observers, etc., so that you can show just what it is you have discovered. It may be a new method of teaching children or the application of some new testing techniques or whatever. Fund-granting agencies which have supported research for a period of time will often be observed to shift some of their funds to support of demonstration projects as research projects come to fruition.

I believe that we have underestimated the importance of good demonstration projects as a means of knowledge dissemination. I also believe that we have overestimated the usefulness of technical journal articles as a means of communicating results of research. Thus, I would hope that we can extend and improve use of demonstration projects. It is important in organizing demonstration projects that resources and plans be carefully developed to do a good job of communicating. This involves architectural considerations so that people who are making the observations of the demonstration can be moved about and can see and hear well. It often involves development of special audio-visual aids. It should involve funding of staff members who can be concerned mainly with management of all phases of observation and demonstration. Too often, I think we've run so-called demonstration projects with good support for programs but with very thin attention to the job of communicating effectively about the program.

A second category of demonstration projects concerns simply the development of outstanding centers in a field and then making it possible for people to come for visits, observations, and limited participation. Hopefully, the observers return home with inspiration and know-how to improve their own programs. This kind of demonstration project may not grow out of specific research. Rather, it may involve the intensive application of the best known techniques by especially competent people. It is likely that when you concentrate extraordinarily competent people in a good facility, the program to be developed will be a whale of a lot better than that which is generally available and it will be useful to make it into kind of a showpiece for others who are involved in a comparable business. I think this is one justification of The Sheltering Arms where we are meeting for this discussion. A variety of excellent resources has been organized here to make available to our state and region a demonstration of good educational practices with retarded children and their families.

Sometimes the term "demonstration project" is used in an inappropriate way. Agencies start so-called demonstration projects without paying particular attention to outstanding quality or without basing their program on any particular research and with but scant attention to needs for effective communication of results. Very often these are simply projects which are deserving of community support but some special funding is necessary to get them launched. They are mainly concerned with getting launched and then to win support from some agency. Where there is lack of provision for making the program highly visible to other professional people, I think it is not appropriate to call these activities demonstration projects in the full and highest sense. Demonstration projects really ought to be developed in places and under circumstances where some specific development needs to be communicated or where you are running an extraordinarily good program. Besides all of that, you have one-way

vision screens and one-way audio situations and all else that is necessary to communicate effectively about your program. You organize conferences, you give speeches and you make your staff available to the community. Somehow or other you really build into the operation the facilities and staff necessary to do a good dissemination or communication job.

A great many difficult problems exist in the research and demonstration aspects of our work. Let us consider a few of them.

1) Financial Support:. Until very recently the amount of support for research relating to mental retardation was extremely limited. No private business or industry of the magnitude of programs for the retarded could survive if so little investment in its own development and improvement was made. The situation is improving now.

2) Personnel. For years the field of mental retardation was a virtual desert as far as professional status was concerned. The field was "deserted" by its professional community. Now, we face vast shortages of needed personnel -- including research workers and it will take much time and effort to recruit and train the needed specialists.

3) Facilities. Almost everywhere -- in institutions for the retarded and in universities where research might be centered -- there is a lack of basic, raw space for research activities. In addition, of course, there are problems of securing specialized resources. Again the situation is improving, but progress will be gradual.

A great many additional problems and issues might be cited, but perhaps the main practical problems relate to finance, personnel, and facilities. Fortunately, progress is being made in solution of these problems -- mainly through leadership of federal agencies.

Let me close here with a brief restatement of what I said at the outset. It is important that all persons working in the field of mental retardation take a part in research -- in inquiry into our field.

SOCIAL ADJUSTMENT PROBLEMS

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As I have understood it, my topic may best be described as, "The retarded adult: social adjustments, problems in the community, social work and services to mentally retarded adults and their parents." Because the word "social" seems to be a key word, I turned to Webster's Dictionary to see how its significance might be recognized there. I found: "That is social which pertains to society in general or has to do with human interaction." Thus, we have a clue to why "social adjustments" of the retarded are and should be of concern to us all.

It is hard to understand the social problems and conditions of adults without thinking about what has happened to them as children. We tend to go along with the thought expressed in verse 15 of Psalm 90 of the Old Testament which makes the following appeal to our Maker: "Satisfy us in the morning with a steadfast love that we may rejoice and be glad all our days." The implication seems to be that what the adult's condition and ability to enjoy life is depends to some extent on what he experienced as a child. Perhaps more and more through the years we have to regard ourselves as having both ability and responsibility for "doing something about it;" that is, for making it possible for children to have the care and experiences that provide opportunity for happy childhood and adulthood. When we knew the needs of people in general, we who are concerned about the retarded must remember and remind others that he is not an exception and that he has the same needs and rights as other human beings.

When I speak of the mentally retarded adult, I am speaking about the "trainable" and "educable" or the "moderately retarded" which is roughly equivalent to "trainable," and the "mildly retarded," which is roughly equivalent to the "educable." According to Leonard Mayo's article in the Encyclopedia of Social Work, "It is estimated that there are 300,000 to 350,000 moderately retarded capable of developing skills adequate for self protection and semi-productive activity," and, "it is estimated that there are five million mildly retarded who are frequently not distinguishable from normal individuals until school age, when they are often identified by their inability to master ordinary school subjects." Most often the problems and possible approaches to these problems pertain to or are applicable to the trainable rather than the educable. Perhaps the best I can do is offer some clues as to what may be involved, as each situation and solution is complex and unique. We are now aware that the solutions for the

trainable as well as the educable mentally retarded must be found in the community, in their home, and in their ability to participate, rather than in the institutions or in our ability to take total responsibility for them. Findings of a study in New York which were published in 1957 show that two-thirds of all the former public school pupils with intelligence quotients between 40 and 50 were living in the community whereas 26% were institutionalized. Since institutional care is more and more regarded as a temporary plan for the mentally retarded as well as the mentally ill, it would appear that more and more of the retarded including the more severely retarded are and will remain among us.

I often find statements to the effect that the biggest problem of the mentally retarded is not the intellectual handicap, but rather what happens to him because of attitudes that do not make possible life experiences that encourage growth and development. This is not to minimize intellectual handicaps, but to encourage alertness to other conditions and handicaps over which we may have some control. A look at what has happened through the years reveals the importance of attitudes in determining what is done for retarded people.

Mildred Thompson states in her book PROLOGUE, "Perhaps by looking back the greatest change which took place during my time was in attitudes - of the family, of the community, and of these working with the retarded, in or out of institutions. The slogan, 'The retarded child can be helped,' has been accepted by many and some communities were providing treating facilities - religious, educational, recreational - all giving socializing experiences. Institutions were becoming centers for stimulating interest. A retarded person whether of high or low mentality was a person in his own right - not so considered by everyone as yet, but by a number that was fast increasing."

Going back farther in history, Stanley Powell Davies describes attitudes in England and in the United States about 1910. The report of the British Royal Commission in 1903 was the first comprehensive study to reveal the close connection between retardation and social inadequacy; however, at that time the focus became not to improve their social adequacy but to protect others from them and their social inadequacy.

About 1910, the prevalent alarm in the United States concerning retardation resulted in many states in the appointment of special investigating commissions, and in vigorous and well organized campaigns of publicity and legislative action directed toward the provision of institutional facilities, sufficient to segregate all defectives. Solutions sought were sterilization and segregation. As you knew both of these measures were unsuccessful and unsatisfactory as solutions for the problem of mental retardation.

Attitudes expressed more recently are as follows: In 1958 a social worker, Howard Kelman, stated: "We can no longer speak with scientific reverence of the retarded as being inherently delinquent or immoral or capable of diluting the general intelligence level of our population through an ascribed abundance of procreative abilities. Nor can we in truth regard them all as hopeless and helpless creatures incapable of positive social adaptations and unable to make useful, though perhaps modest, productive contributions to the community."

Dr. Mayo states, "The mentally retarded person should be served with as little dislocation from his normal environment as is consistent with the special character of his needs. These needs should be met as close to his home as possible and in such a way as to maintain his relationships with his family and peers."

President Kennedy's statement regarding the need for a national plan in mental retardation states, "Our goals should be to prevent mental retardation. Failing this, we must provide for the retarded the same opportunity to full social development that is the birth-right of every American child."

In describing the goals of an independent-living rehabilitation program, Arthur Segal's attitude is that this multi-disciplinary service is "designed to help mentally retarded adults live as adequately as possible in their own homes or in foster homes. The program is built around the belief that in most instances the mentally retarded need not be institutionalized - furthermore, that they have a right to grow emotionally and develop as much independence as possible."

In these more recently expressed attitudes of specialists and leaders, we have the basis for a new approach to mental retardation. We no longer look to mass approaches to the problem but rather to a variety of approaches that convey a hopefulness and expectation that a retarded person can participate in finding solutions for his problems. We know that in spite of these expressions of confidence in the retarded human being, professional people and the general public remain ambivalent. We say that this is a democracy and that all people have rights and yet we need to guard against making exceptions to this when we consider the retarded adult. Undoubtedly there are many reasons for this, some of which may have to do with our lack of knowledge and our failure to individualize.

When we consider what attitudes are or have been, it doesn't rule out the possibility that there were and are great differences among individuals in attitudes. Stanley Powell Davies gives an example from Dickens' book, *Little Dorrit*, in which Dickens gives a description of a mentally retarded individual which is in accord with modern understanding. Another example of an attitude expressed

in literature before 1914 may be found in Edgar Lee Master's, Spoon River Anthology. Willie Pennington's epilogue is as follows:

"They called me the weakling, the simpleton
 For my brothers were strong and beautiful,
 While I, the last child of parents who had aged,
 Inherited only their residue of power.
 But they, my brothers, were eaten up in the fury of the flesh,
 which I had not,
 Made pulp in the activity of the senses, which I have not,
 Hardened by the growth of the lusts, which I had not,
 Through making names and riches for themselves.
 Then I, the weak one, the simpleton,
 Resting in a little corner of life,
 Saw a vision, and through me many saw the vision,
 Not knowing it was through me.
 Thus a tree sprang
 From me, a mustard seed."

Perhaps many mentally retarded in the past have benefited from attitudes such as these. However, larger numbers were affected in a vital way by attitudes and actions of leaders who regarded handicapped people as a menace and a threat. Today, I believe that leaders convey that the mentally retarded person has become one of us; he has become a human being. One of the things that has helped many recognize the retarded as human beings has been to know individuals who are retarded - to know children and adults who are retarded and to know a good deal about them. When we do, we can see how each one is unique in his ability to respond and to learn.

If we are really going to be of help to the mentally retarded, we need to know something about the problem areas in order to understand what can be expected and where help may be needed. I shall deal briefly with a few problem areas which seem most important to me.

The mentally retarded sometimes remain children longer and may in some ways remain as dependent as children all of their lives. This is especially true of those who tend to be labeled trainable. In speaking of the family group, sociologists have pointed out that dependency of children on their parents must be temporary rather than permanent. They point out that a family should in due course help in emancipating the child from his dependency on his family. Parents who have come to understand and accept the greater dependency needs of a retarded child sometimes go overboard in their effort to fulfill parental responsibility. Help is often needed in assessing what is helpful and what is reasonable to expect of them. Families are smaller, homes are smaller, all members must meet many needs outside the home. Thus help in the home and activities outside the home may make it possible for the more dependent adult retardate to remain in his own home.

Two sources of information pertaining to the trainable adults that are most helpful in considering what might be the special problems in maturation and in dependency are the Minnesota Conference Committee booklet, *How They are Grown* which was published by the Department of Public Welfare in Minnesota and a book about which you already know, Laura Dittman's, *The Mentally Retarded Child At Home*. Mrs. Dittman has a section on adolescence dealing with problems which may continue into the young adult years. She points out that the needs of the adolescent person are to be on his own and to have continued close supervision. This conflict is not unusual for any teenager. Other needs mentioned which are important when we want to help and when we want to provide resources in the community are as follows: Growth in social know-how, learning useful work, and ample recreation and leisure time outlets. Thus, while we recognize their greater dependence on the parents and family we must also recognize their need and ability to be, or to learn to be, independent in many respects.

The New York study showed that most parents had given considerable thought to the future of the retarded adult knowing that the time would come when they could no longer care for their retarded family member. Most parents had made more or less definite arrangements to keep the retarded person in the community usually expecting that his siblings would be able to take care of him. In Minnesota state guardianship is one of the possible provisions for having a social agency assume responsibility when a parent can no longer do so.

Another problem of the mentally retarded adult may be a poor self-concept. According to Elsie Stephens, "His family, friends, and acquaintances often attempt to force the fact of his low intelligence upon him. They are likely to make the retarded person a scapegoat for the fears that all people harbor about their own inadequacy. Because our culture places great value on mental prowess, many persons who fall short of their ideals tend to take out their frustration on others. The victims are often individuals who represent their worst fears. The fact that an aversion toward mental defectiveness is almost universal, is evidence of the extensiveness of the fear. These feelings of aversion are apparently incorporated by the defective himself. Until the patient is separated from this fear-ridden image of himself, he will continue an excessive use of denial as a defense, which, in turn, interferes with maximum adjustment. It can also be a pre-disposing factor to physical and/or mental illness or to precipitating him into anti-social conduct which may bring him into conflict with the law."

Howard Kelmen states that, "On the whole, he lives a life marked by frustration, social constriction, and with constant and all too obvious reminders of his failure as a human being. The

retarded person is not as we knew, without feelings, sensitivities and an awareness of how society values him. He receives these perceptions of the world in kind and views quite accurately the role into which he has been cast. He is then further penalized and castigated by the very same value system and social institutions which have made him what he is."

In describing the problems of delinquent girls, Mrs. Konopka states, "Popularity has a high value among adolescent girls, especially those excessively dependent on peer acceptance for a feeling of self worth. A void left by lack of friends is usually filled with a love relationship or through the crowd."

Thus we have a problem for the retarded which can only be solved by our own self awareness and education plus provision for experiences that may contribute to feelings of being valued as a person.

Another problem which is certainly related to others might be worth mentioning; this is isolation. According to the New York study about half of the severely retarded adults were able to communicate in a limited way with other family members without developing a genuine give and take relationship. Minimal relationships, mechanical obedience to commands, and, in a few cases, an almost "vegetable" kind of existence was said to characterize the remaining one fourth of the cases studied.

It was concluded that their mental handicap together with their inability to get around by themselves interfered with their ability to keep friends of their own. Only one half of all the former pupils were said to have friends. The majority of friends of the retarded were of normal intelligence and either the same age or older than the retarded adult. Age played a role, however, in as far as the older retarded found it more difficult to make and keep friends than the younger ones. Parental attitudes, acceptance and rejection, encouragement of independent behavior or over protection were equally important in determining the social life of the retarded.

Our ability to accept the mentally retarded may depend greatly on whether or not their behavior is socially acceptable. There seems to be wide acceptance and considerable evidence that consistent training and a generally satisfying life situation make it possible for the mentally retarded person to behave in a socially acceptable way. The booklet, *Now They Are Grown*, contains the following statement: "The individual who is classed as trainable does not develop mentally and often does not develop physically in the same manner as do normal persons, nor does he have the same interests. He will not be able to take on the same responsibilities. We know he can be helped to have interests satisfying to him,

that he may be trained to behave in an acceptable way and that he may be taught to accept responsibilities which he is capable of handling. We also knew that he can be accepted, understood, respected, and enjoyed by others. But he can only be so to the degree that one accepts him totally and realistically, with his limitations as well as his capabilities."

According to the New York study, most parents felt that their retarded child was easy to get along with and presented no major difficulties. Most parents felt that the child could be left alone safely while a few were concerned with what might happen. Concerns were expressed mostly about sexual exploitation: "Retarded girls may permit strange men to enter the house and take advantage of their ignorance." In a large majority of cases, the lack of parental concern appears justified. Most of the retarded had apparently learned to keep out of trouble as indicated by the small number of accidents occurring at home.

When we speak of socially acceptable behavior, we often are concerned about the mentally retarded person's interest in the opposite sex. In speaking of the teenager, Laura Dittman states: "Parents of all adolescents struggle to find middle ground in their actions and feelings about how and when boys and girls get together. When there is retardation, parents are even more deeply concerned since they feel the consequence of adult sexual drives with youths who are still children in judgment, knowledge and ability to control. They may also fear that their own child may be taken advantage of by others. It is important to recognize that responsible parents of all teenagers have these same fears; at the same time accepting that the problem may be even greater for the retarded."

"There are many retarded teenagers who do not seek or desire intimacy, who are interested in others but without the sexual attraction as a factor. They continue to select friends from their own sex. Others may closely match the normal adolescent in awakening interest in those of the opposite sex. For these, our job as parents and citizens must be to help provide acceptable outlets for sexual desires, channel energy into other activity, and to help the adolescent control his own action. In many cases, this amounts to a continued need to supervise and watch over."

Mrs. Dittman also points out that teenagers want rules of conduct and etiquette. They make up their own if society does not make them clear and meaningful. Even though movies and magazines show extremes of behavior, today's teenager searches for rules which will tell him what to do, what is right. Lessons can be given in the simplest things: how to behave at a dance, how to introduce people, how to use a telephone, to hold the girl's coat, and so on.

Again when we speak of socially acceptable behavior, we are often concerned about whether or not the retarded person may become delinquent. Dr. Lawsen G. Lewry has been quoted as concluding that, "intelligence is only one of the many factors which may produce objectionable reactions," and that, "factors of personality, the integration of the emotional and instinctual life and in the social situation are far more important than a mere question of intelligence." Stanley Davies concludes as have many others, that the mentally retarded frequently come from peer environments and are deprived of opportunities for wholesome contacts and are therefore more likely to come under influence that will lead them in delinquent ways.

According to the New York study, in spite of the fact that many retarded ventured out by themselves, few get into any trouble. Leaving out those who get lost or ran away, only 7% had gotten into any trouble that might have been of concern to neighborhood. Moreover, most offenses were of a minor order, such as vagrancy, or peddling without a license. Parental statements were substantiated by police records which yielded identical figures of retarded adults who had gotten into trouble. Thus it would appear that many factors other than mental retardation contribute to the possibility that a mentally retarded person might become delinquent.

Some Some of the problems of the mentally retarded person, such as mental illness, poverty and unemployment are now widely recognized as problems of national concern and as problems that the mentally retarded person shares with many others. Sarason and Gladwin point out that the incidence of psychosis in the mentally defective population is apparently much higher than in the general population. This is understandable when one reads the following definition of mental health by Julius Schreiber: "Healthy living or mental health - means that an individual has found a reasonable measure of peace with himself and with his environment. It means that an individual is able to pursue reasonable, purposeful goals; may use his capacities and talents fruitfully; experiences a sense of security, of belonging, of being respected; has knowledge that he is liked or loved and wanted; has a sense of self respect, of self reliance and achievement; and, in addition, has learned to respect others, accept others, to love others, to live fairly and in peace with others." This is difficult to achieve for any of us and particularly for anyone who is handicapped by his own deficiencies as well as the attitudes of others.

In speaking of learning opportunities so necessary to adequate development of intelligence, Dr. Mayo states "The inferior performance of slum area children is believed to be related to four broad influences in their development: 1) lack of motivation, 2) a home that fails to develop adequate modes of thinking and perceiving, 3) family structure that is emotionally crippled and

4) lack of adequate social facilities is health, education and welfare." Thus, in poverty situations we find more children who appear mentally retarded.

Regarding employment of the retarded, Miss Mildred Thomson makes the following significant statement, "I fear that the unemployment problem will be more acute for the retarded than for others. This is certainly an area where research, vision and ingenuity will be needed to make certain that occupation is provided - as without it, delinquency will certainly increase." She also expresses concern about what the future will hold for persons who are in the higher levels of retardation. She states that certainly they will be more understood and receive improved training. Without doubt, many once considered retarded will be found not to be as retarded as in the past.

The New York study showed that 27% of those severely retarded residing in the community worked for pay. In addition 9% had previously worked but were without paid jobs. Thus we have individuals in the community who want to work and who are able to do some kinds of work but who are increasingly unable to compete for employment. For some,, day activity centers or sheltered work-shops may be the answer.

Having looked in a broad way at problems as they may be of concern to the mentally retarded person and his family or to the community in general, I would like to give some consideration to ways in which the social worker ~~us~~ attempt to help. Social workers in general are concerned with social functioning which represents the interplay between the social environment and the individual - each of which is a composite of various forces. Helen Perlman describes common ways in which a social caseworker may be a helping person, "We help the client to know more clearly and surely what he wants and ~~thet~~ what he must do to get it; to mobilize his energy and stretch himself for attaining goals with realistic hopes; to express and share the feelings which block or drain his energies; to see himself and his problem and its solution with greater clarity and realism; to focus on one part of a problem at a time; to feel safe and at one with the person who combines compassion with competence; to gain know-how; to exercise consideration and weighing of choices and decisions; to take trial action on the basis of increased security, knowledge, and provision." She also states that the goal for each specific client must be unique to him and to his situation.

Another social worker, Florence Hollis, states: "Planned help by the casework method involves the fullest participation of which the client is capable. Casework treatment, thus, does not do to people or for people, but instead, consists of working with them. In many situations casework treatment may be given in

collaboration with other kinds of professional services or the caseworker may consult with members of other professions." In the field of mental retardation it seems essential that the social worker collaborate with members of other disciplines.

In describing working with the mentally retarded adult in a rehabilitation setting, Arthur Segal describes the handling of an emotional crisis in the workshop. He states "At that time the caseworker is in the best position to help the enrollee to view the situation he has just experienced, to deal with the emotions he is expressing and to clarify the circumstances surrounding the incident." He goes on to point out that a time interval between the incident and the discussion gives the client time to solidify his defenses and makes it harder to use the episode constructively.

The social group worker on the other hand, "assumes an active role at the start helping the enrollee to feel comfortable in the group, to discover his role in the group, to realize his strengths and to relate directly to other members." As his self confidence grows, the enrollee finds himself able to reach out to his peers. His identification with the group leads to the development of group goals and a structure within which to work. He helps to develop group norms and takes part in the election of officers. He takes pride in his group accomplishments.

Social workers may function as administrators, as community organizers, or as consultants in a variety of settings in order to contribute to attaining goals that are being recognized as important for the mentally retarded. However, the responsibility for attaining goals is not the social worker's alone, but belongs to every agency, profession, and individual who is concerned about human welfare.

President Kennedy's panel on retardation concluded that "The richer and more easily available all services become, the less need for special services for the retarded. Even if there were no need for economy, the conviction that the retarded should be viewed as a part of, rather than apart from, their fellow citizens would be sufficient reason to advocate that wherever a general Betting or service or a general law can properly and effectively embrace the retarded person it should do so."

To quote from a statement by President Kennedy, "Prior to 1950 relatively little attention was directed to the problem of mental retardation by either the federal or state governments or in fact by private groups. During the past decade, however, increased interest and activity have been stimulated by a few foundations, by the demands of parents, by interested lay and professional groups and by members of legislative bodies who have been convinced of the urgent need of progress in this field."

According to Dr. Mayo, the concept of area centers for the retarded is now coming to the fore. He describes the center as a grouping of specialized resources serving as a concentration point for services to the retarded of a specified geographical area. Problems of the retarded can be viewed in the context of his age group, of the family, or of society as a whole. When we are in the position of helping a particular retarded person, problems related to his age group and family are most meaningful to him.

As you know, there have been some laws already put into effect as a result of the 95 recommendations of President Kennedy's panel on retardation. Many of the recommendations are the basis for legislative goals. Most of the provisions pertain to children. Some pertain to training, facilities and salary in a way that will certainly also affect the mentally retarded adults. Some pertain to the assessment of services and programs to meet employment needs and to assure that the needs of the mentally retarded will be given appropriate attention and priority. Such assessment is the responsibility of the Department of Labor and the Vocational Rehabilitation Administration. Thus, we have some exciting changes taking place and much reason to be optimistic about the progress being made. There are still, however, many serious problems for the retarded both in attitudes and lack of services. Both the mentally retarded and "society" will benefit from continuing attention to them.

THE ROLE OF INSTITUTIONS

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In discussing institutional aspects of the problem of mental retardation, I will be speaking in a sort of panoramic way. Over the past twenty-five years or so, my concern with retardation has been from a number of different vantage points - as a caseworker in one county, as a director in another rural county, and for several years as director of the division responsible for public welfare services to the mentally retarded here in Hennepin County, and most recently as assistant administrator of the largest urban public welfare agency. Some twenty-five years ago, there was a group of inter-related families along the Minnesota-South Dakota border near where I was working. At that time, Minnesota already had a substantial tradition and approach to providing public services and assuming public responsibilities for the mentally retarded. In those days - 1939, 1940, and the immediate pre-World War II years, it was quite common practice in the agricultural areas of the state to look to state institutions for the mentally retarded as a source of inexpensive farm labor. Young men in the late teens and early twenties were quite routinely placed on supervised farm jobs with some insignificant salary of ten or fifteen dollars a month paid for their limited labors, and often times they were cheated and taken advantage of in terms of their earnings from those labors. Supervision of the retarded was a basic responsibility of each county welfare department. The county Welfare departments were relatively new agencies themselves at that time; officially, the county welfare system of public welfare in Minnesota had just started on the first of July, 1937. The functions of services to the mentally retarded outside of institutions had been delegated by law from the old county child welfare boards, a group of people serving in appointed roles without compensation, to the county welfare departments as agents of the director, now the Commissioner of Public Welfare of the state. This date of 1937 was significant because this was a follow-up in the respective states to implement the Social Security Act, which had been passed by Congress in August of 1935. This necessitated special sessions of state legislatures in many states, including Minnesota, to create new programs and laws to take advantage for the first time of such things as the categorical aid programs - Old Age Assistance, Aid to Dependent Children, Aid to the Blind, and later on some of the new categories. Included in this program was the delegation of responsibility by the Commissioner to counties to serve as his agent on behalf of any mentally retarded ward residing in their respective counties.

We in Minnesota preceded most states in assuming a responsibility for the care and support of a mentally retarded individual who, upon

due legal commitment in the probate court of the county of settlement or residence, became the financial and custodial responsibility of the state of Minnesota upon his admission into the state institution. We have the historic institutions of course - Faribault, Cambridge, more recently Brainerd and some of the annexes for defective delinquents at the St. Cloud correctional facility (which has recently been dissolved) and the small annex in relationship to the Reformatory for Women at Shakopee. It was basic that the county, upon receiving a referral, anticipating that a child or adult might be mentally retarded as arbitrarily classified in terms of psychological test results, would be committed as a condition of being admitted to a state custodial school or facility. Commitment had a number of unique, interesting, and, I think, pioneering purposes in itself. Traditionally, we would say to the family that the two main purposes of commitment are: first, to secure a valid position on the waiting list for admission to the institution, and secondly, to provide some insurance or assurance to the parents and family members that if anything happened to them so they were unable to exercise their parental responsibility on behalf of the dependent, retarded individual, they might be assured that the process of legal commitment as mentally retarded would provide an umbrella of protection for the retarded son, daughter, or relative under the name of the state of Minnesota and the county in which they lived; they need not worry about him. There are a number of other advantages and unique aspects of this commitment than for purposes of getting on the waiting list and admission to the institution. It set a pattern, a precedent of financial liability. It was a transfer of financial responsibility from the family to the state; this financial responsibility began on the day the person entered the institution and continued as long as he might be there. It was quite typical as recently as, say, ten years ago, for the family and the county welfare department and the state all to recognize the mutual benefits, financially, of waiting patiently for the institutional space. This pattern remained essentially the same over the past twenty-five years. Routinely, you must inform the family, "Yes, there will be a waiting period of two to three years - more likely three, and possibly more - but it is worth waiting for and eventually space will be offered in the institution." We had, in Minnesota, a very outstanding, pioneering person - I don't think she would mind my making a personal reference to her - our venerated Dr. Mildred Thomson. Her view was that this is a "tight ship, no monkey business." This is a serious responsibility, to serve as the guardian of mentally retarded wards. The waiting list for admission is secret. We, the state of Minnesota, must exercise to the best of our ability this responsibility. Social workers out in the various counties were to keep her informed in detail about what went on in the adjustment of the retarded ward - his community relationships, his social activities, his personal behavior. We used to ship material by the basketful, almost, to the state office. Dr. Thomson was dedicated to protecting, serving, helping, improving public understanding, and improving the lot of the mentally retarded individual. I think

a permanent place in social history must be given to Millie Thomson and the pioneering work she did here.

I think of some other significant happenings. I recall the administration of Governor Youngdahl and the social reforms that he instituted here, not only in mental retardation, but in mental health; I recall the rather dramatic date when the restraints were removed from patients in mental hospitals once and forever. I remember, too, his concern for the continuing problem of keeping a "finger in the dike," building a few more wings and annexes, trying to keep up with the population increase, and never, never making much progress in the swelling waiting list of two to three or more years. Everyone recognized the state's responsibility but never wanted to change it particularly. The alternative meant a transfer of greater responsibility to the family or to the local communities which, up until about 1950, were relatively indifferent to any particular concern for the retarded. The retarded were social misfits to most families, often kept hidden away. 1950 I recall as a significant landmark for the change that has taken place since. This was the year when a group of parents, with some behind-the-scenes encouragement, help, and direction from Mildred Thomson, organized the early humble beginnings of the first parents' association for retarded children, which went on to become the Minneapolis Association for Retarded Children, the Minnesota Association, and eventually the National Association for Retarded Children. Today this is one of the most significant, most effective, and most dedicated volunteer, non-profit groups in operation. I recall vividly that in those early organizational days we social workers were quite skeptical as to what kind of organized pressure group and complaining group was developing, and were wondering how we were going to cope with them as they became stronger and more settled in their purpose. With some embarrassment and some pride, I think back now and see how we were able to coordinate our goals, interests, programs, and purposes with theirs, and how it has worked across the nation to the advantage of the retarded and has led to so much significant legislation at state and national levels.

I'm sure some of you have already visited the institutions, especially Faribault and Cambridge, the traditional too-large, run-down, under-financed, over-crowded, under-staffed institutional settings that we, with considerable shame, call our modern public state-operated institutions for the retarded. Just yesterday, I noticed in the paper reference to the governor's message and recommendation that funds be appropriated to provide something like 570 additional staff positions. I can tell you from personal experience that every one of those positions is needed, and a good many more. This is a sad reflection on our state performance. Today the waiting list is still as great, and, if anything, I think the problems and the pressures are greater.

During these past twenty-five years, we have seen a radical change in the philosophy about institutions. We have seen the so-called orphanages for young dependent or neglected children literally disappear. We have seen institutions up-date their purposes and the old, traditional reasons for existence have changed radically. Today, an institution of any kind has little justification for existence unless it is carrying on a specific program. We saw the old state public school at Owatonna, which was for dependent wards of the state - usually normal children who were deprived of parental care and support, but not suitable for adoption because of their age - close down in about 1943. The state wards were placed through their counties of settlement in a variety of foster homes, adoptive homes, and non-institutional settings. The facility at Owatonna then became a residential school for educable mentally retarded children. We saw several church-related and private institutions for children change their programs. One I am very familiar with is the Vasa Children's Home at Red Wing. As they looked at the various needs they settled on a new program of services to the mentally retarded infant and young child who needed protective, custodial services. In order to be admitted, the child had to be committed and on the waiting list for admission to Faribault, and at the time space became available in Faribault, he had to be transferred. If the family for various reasons decided to pass up the available space, then the facility at Vasa could no longer be used for the child. This policy was dictated in large part by finances. Having a child placed in Faribault meant that the family would pay only a token amount, less than \$10 a month. There have been various attempts to develop a formula for family participation in the institutional cost, which is about \$125 per month per capita. Now it is about \$10 a month "head tax" assessed against the counties. As long as the state was paying the cost through legislative appropriations, no one could criticize something for which he wasn't paying. When you start dreaming up better methods and developing better resources, then it pinches somewhere in terms of who is going to pay for it. With the development of parent groups and the consequent greater openness about admitting having a retarded child, things began to change. Today's concept of the role of institutional care has changed, too.

Today we are raising serious questions about continuing the old, obsolete concept of commitment of the retarded person. Really, what purpose does it serve? If it is only to provide a place on the waiting list, should there be a waiting list? Is there some way that the tax appropriations of the state could be distributed in some more equitable, fair fashion to encourage the development of alternative, local community resources? A family may be told, "You must somehow get along with your retarded child for another two and a half years, even though it may be damaging to the family relationships or impede the normal growth and development of other children; it's your problem; if you can't live with it, you figure out some

other way of managing until the day arrives that your name is reached on the waiting list." Obviously this is not a very practical or happy solution. Child welfare programs and foster placement programs of social agencies have become more sophisticated and more wide-spread. It became obvious that a foster home might be the answer in certain emergencies, if space could not be provided in the state institution. So we have seen, here in Hennepin County and in other counties as well, the development of auxiliary or "standby" foster home placements for children who must, for medical or social reasons, be removed at once from their own homes. In Hennepin County we have about 250 retarded children placed in licensed foster homes, presumably under guardianship and on the waiting list for space in a state institution, but increasingly, we are questioning the validity and the necessity of commitment. We have concluded that if our only purpose is to maintain some kind of a financial restriction over the families' choices, it doesn't merit continuing it.

We have seen the development of laws which make it mandatory for the school district to provide public school special class facilities to the educable child and which provide financial inducements for the school district to develop, on an optional basis, special classes for the trainable retarded. We have seen the legislature accept some responsibility for encouraging day activity centers for the retarded. This began with a modest appropriation for a two year pilot demonstration project. Then, the pilot aspect was removed and something like \$155,000 was appropriated to encourage the development of day care facilities for the retarded. Quite a number of these have been opened, some for preschool groups and some for older groups. The current message of the governor provides for a substantial increase again - something like \$550,000. We have seen, on the Federal level, influenced by the tremendous personal popularity of President Kennedy and his personal interest in retardation, a tremendous legislative interest at the Congressional level.

We have here in Minnesota a combination of many things which I feel are strong, good, and unique, and some residual carry-over of things that are pretty obsolete. My own agency, as the largest urban public welfare department, has a sufficient caseload of mentally retarded to justify a highly specialized approach. We are serving a group of approximately 1200 mentally retarded adults and children in the community, plus what we technically refer to as a "suspended caseload" of approximately an equal number in the institutions. We have a group of approximately fifteen full time staff people who are dedicated to the proposition that serving the mentally retarded is the most important field of social work. Many of these people have literally made a lifetime career in just this one area of service. One aspect of our approach is the recognition that many of these people who were placed in institutions ten or fifteen years ago might get along all right back in their community now, as adults, if they

could apply their physical maturity to the simple jobs such as work in kitchens, bakeries, laundries. Many of them are already doing this work in the institutions. If someone would take the time to follow through and find appropriate placement for them in the community, many of them could get along quite well, under supervised, sheltered conditions. The typical caseworker has a mixture of adult and child cases, but many of the adult retarded are individuals who have spent some years in the institution and who have come back to the community. Actually we have some mentally retarded wards • currently in the community under the supervision of a caseworker earning more money than the caseworker probably earns himself. We have wards with bank saving accounts (usually in joint saving accounts with the assigned caseworker) which have accumulated to amounts that are quite amazing. I can think of several that have been more than \$12,000 to \$14,000, frugally saved and put aside to earn interest, often in the hope that someday they would be permitted to marry and establish their own households. This raises a lot of other interesting problems. An agency as large as ours permits specialization. We have one man, Mr. Prosnick, who specializes full time in finding appropriate employment for mentally retarded and some mentally ill persons. He has a consistent record of about six or eight new job placements of retarded persons each month, and has a cumulative case load now of about two hundred retarded individuals who are working in Minneapolis or its vicinity, generally doing very well on the job, usually completely self-supporting, reasonably happy and productive as citizens and residents of the community. They have counterparts who are still in the state institution because there isn't some formal organized effort to bring them out and because there is some problem of how to finance a care plan. In 1957, Minnesota somewhat belatedly accepted the opportunity to establish a new categorical aid or public assistance program called Aid to the Permanently and Totally Disabled, aid to a person who literally requires the care, help, or assistance of another person at least part of the time. A person who is able personally to come into the office to file an application or inquire about it is likely ineligible by virtue of the fact that he got there under his own power. This program provided a very limited resource, the extent of only \$70 a month. But this resource since 1957 has been an added incentive for bringing back to the community many mentally retarded persons who would have had no resources otherwise. This grant has often served as "seed money" to bring out some kind of supplemental resource either through local general assistance from one of the townships or municipalities, or Social Security, Old Age and Survivors' Insurance. Some combination of these things has often made it possible to finance the local living arrangements and thus make possible a community adjustment.

What of institutions for the future? I am convinced that we are never going to get sufficient legislative appropriations to build the additional state facilities, to modernize the existing ones, to staff them the way they should be staffed, to absorb the

additional population increase in Minnesota, even if we felt institutional care was the best thing. I think it might be preferable for many of the retarded if we could convince the legislature to participate financially with local communities in developing local resources where the person has residence, where his family and relatives and friends and happy memories are located, and develop various kinds of local alternatives to institutions. Vasa is an example of a facility developed with church support; we have another example of this in Lake Park-Wild Rice, which serves primarily the school age retardate with emotional problems. We have seen the development under private auspices of some small private institutions or oversized foster homes.

Discussion period:

Question: Could you give us a little more background about the changes in the guardianship law which are being considered?

Answer: I'm not sure I can give you much of the technical and legal arguments, but in recent years, the question has arisen as to just what the purpose of commitment is other than to serve as a device for maintaining the waiting list for admission to a state institution. If some real emergency arises and if space can possibly be provided in already overcrowded situations, the emergency in itself will permit consideration of placement and whether the person is on the waiting list or not won't make much difference. Ironically, I think back to the efforts put in to educate the medical profession about the advantages of guardianship, in the past, and now it is often the doctor who urges this at the very time that we are exploring the idea of abandoning the guardianship process. Many attorneys have raised questions about the extent to which the civil rights of the individual are being imposed on, because commitment has meant that at the time the court declares the person to be retarded and a ward of the Commissioner of Welfare, the commitment remains in effect for the life of the individual unless revoked by the court itself. In our modern day and age, commitment as a legal protection is perhaps superfluous, because society today should be and, I think, is responsive enough to want to meet the needs of any person dependent at a given moment; the fact that one may or may not be retarded is incidental. As human beings, as citizens, as residents, they are entitled to the same kinds of protection, help, and service as anyone else. The pendulum seems to be turning. Some states, ironically enough, are just starting to discover commitment procedures at a time when we in Minnesota are seriously considering whether they should be abandoned as outmoded. I feel that it really serves no good purpose any more. It labels a person, it implies a dependency of a permanent lifetime total nature, it has removed from the person a number of basic rights and privileges enjoyed by other normal citizens - the question of the right to marry, the right to own and operate an automobile.

Question: What can a family do after a child is in the institution if they feel that he should be returned to the community or home? Do they have anything to say about it?

Answer: When a child is in an institution, there is a continuing liaison between institution, family, and social agency - usually the county welfare department - for questions like vacations, visits, or perhaps coming out for an extended period. Usually, this poses a dilemma for institutional management because the demand for space exceeds the supply by so much. The minute there is a space, there are a dozen candidates for it, and the family must be told, "If we approve the discharge now, we cannot promise you the space will be available six months from now or whenever he might return." Usually, when a child or adult comes out, he wouldn't be likely to return unless he became involved in a very serious emergency. It doesn't happen very often that the family wants to bring the child back. I think often as the retarded individual grows older and the family reunites around its remaining members, this one member is "frozen out," so to speak, which is unfortunate. The county welfare department keeps in touch with the individual in the institution with such things as birthday cards and Christmas cards and often serves as a link to interpret criticisms, complaints, or observations of the family to the institution. It is being proposed in this legislature that the state should participate financially on a matching basis in meeting the needs of mentally retarded in their own communities in lieu of institutional care. We can argue that this kind of matching participation would be less expensive and more constructive and more likely to motivate the local communities to develop facilities and assume responsibilities if they have a partnership arrangement with the state. I doubt that it will pass this session, not because it doesn't merit favorable attention, but because of the realities of the tremendous fiscal pressure and the hard decisions as to where the added revenue can be raised.

Question: Does this Mr. Prosnick help the retarded who remain in their own homes and do not go to institutions?

Answer: Oh, yes. The fact that they have, or have not, been in an institution is just incidental. It's just the realistic thing as to whether he can sell the particular kinds of skills, personality, and reliability of the candidate to some responsible employer. This will vary from time to time, depending on the supply and demand of the labor market. I just marvel at how successful he is in finding placements that work out so well. He builds up a relationship, a sort of nucleus clientele of employers who find many advantages in hiring retarded individuals. Their reliability, their willingness to do some things that would make more ambitious employees restless - some of the messenger jobs, car wash jobs, bakery, nursing home aides - there are quite a number doing very well in the community.

One significant thing I should add about commitment processes. I think of a court decision in which a commitment was ruled invalid because the child did not have proper legal representation in the form of a guardian ad litem. The significant thing about this was that it threw a cloud over the validity of all other commitments, and quickly led to an added safeguard that in every hearing in mental deficiency, there must be an independent guardian, an attorney appointed at court expense, if necessary, to defend and protect the interest of the child. You must remember that in a state like Minnesota, with the exception of the three metropolitan counties, responsibility for hearings in mental retardation, epilepsy, mental illness, and alcoholism as well as probate court hearings, are conducted in the probate court. Until a few years ago, there were no special qualifications for a probate judge other than that he won the election. Some of the judges could not be expected to know very much about the law or the social implications, and yet within their province was the decision as to whether a person was or was not a retarded child. Today it's just a routine part of the court process that there be a guardian ad litem to represent the interests of the retarded individual.

Question: What about sterilization?

Answer: There are laws on the books to provide for it, and some very stringent safeguards. We have vacillated back and forth in attitudes toward sterilization. The practice has been very limited in Minnesota and it has never been a very significant technique here.

Question: I was wondering about the percentages of cost which parents are supposed to carry.

Answer: The parents of a minor child are expected to pay, I believe, ten dollars a month now, unless their income is on such a high plane that they can assume the entire cost. In this area, too, we have gone through a number of changes. There was a time when parents were expected to pay 52% of the cost on the rationale that they could then qualify for a dependent's allowance on their income tax. Now, unless the ward in his own right has an estate or income sufficient to cover the cost, the charge to parents is a token ten dollars a month - the assessment against the county of commitment is ten dollars a month. There was a period when counties made a systematic effort to collect this from families. Today, it is pretty much a recognition that the cost of care is met entirely by the state. Again, this is a controversial area that is treated in different ways by different states.

Question: What about those who are total care patients and outlive their parents?

Answer: Then the charge would be the ten dollars a month assessment against the county. Basically, as a state policy, the

clothing needs are met by the state, but I believe they do encourage families to supplement.

Question: Would you talk a little bit about the problems related to finding boarding homes?

Answer: We have about 900 licensed boarding homes, and as we recruit them, as we license them, we usually label the particular kind of child and the numbers that they might best serve. Usually they all like to serve the normal child as young as possible. Rarely are we able to persuade a home to be interested in special service to the teenager - understandably. To find a home that will consider taking a mentally retarded child is extremely difficult until they have had some experience and satisfaction with this. It's interesting to note a pattern that exists. In some families, where perhaps the mother once served mentally retarded children, daughters in this family later on are more likely than others to offer their homes and be licensed and provide the same service. The pattern seems to be based on personal exposure, involvement, and satisfaction that may follow through for several generations. Another episode I recall has some bearing on this. At a meeting a few years ago, I remember sitting down next to a woman from Fergus Falls. She introduced me to her little daughter who was about ten or eleven years old. The child was beaming, well dressed, well groomed, quite pleasing in appearance. The mother said to me, "You know, today I brought my daughter along and we shopped all day at Dayton's and not a single person turned around, stared, or raised any comment. A couple of years ago, I would have dreaded the thought of bringing my child along with me because I would have sensed the ostracism and social rejection of this child. Today, at Dayton's, nobody even bothered to raise a question." Relate that to the recruitment of foster homes. Today we have a much more sophisticated understanding and acceptance, and I credit much of it to the public information and education, and the exposure of retarded children and the acceptance of them. We are always short of homes. We use all of the typical public relations gimmicks of advertising, news releases over radio and television, posters on the public buses, but in the final analysis, our best source of recruitment are people who have actually served or worked with retarded children and by friends of the retarded who somewhere along the line recruit other people directly. It's not too often that we can sell the idea of specializing in work with retarded children the first time around.

Question: What kind of requirements do the homes have to meet?

Answer: There have been a lot of stereotyped notions that you had to have so many square feet of space and cross-ventilation and some certificate of emotional stability among the members of the household, but today we have just a practical approach. Is the composition of the household such that there would be reasonable sleeping space? Is there anything about the house that would violate

the fire marshal's safety standards or the basic health requirements? What occupation the parents are in, income level - these things are sort of irrelevant and incidental. Some boarding homes have only one parent. There is a basic rule that the number of foster children plus the family's own children should not exceed five. When the number exceeds five, it is more a residential institution than a family grouping. The license usually specifies the number of children the home can care for. With the retarded, there is some flexibility when, for instance, the children being cared for are the helpless "crib" infants. The license is renewable annually. It does require the fire marshal's approval for physical safety and is subject to periodic visitation. A file on each home usually represents the cumulative experience of the various caseworkers who have had dealings with the home. The rates are usually quite standardized and tend to run higher for the care of a retarded child than for a normal child. While it's difficult to find enough homes for retarded children, it is even more difficult to find homes for some children of minority groups. With the retarded small child, the racial background is usually unimportant, but as the child gets older we have more trouble. The average rate runs between \$125 and \$150 a month; sometimes it may run \$175 for the really disturbed problem child. The rates for a normal child of similar age probably would run around \$80 to \$90 a month, so there is a substantial difference.

Question: Is it more difficult to find boarding homes for adult retardates?

Answer: It probably is, if you talk about boarding homes in the same sense that we do with children. But for the typical adult coming back into the community from the institution, the placement is likely to be a kind of group boarding home or rooming house, a larger, more impersonal setting many times. We do have, I suppose, 300 or so homes in this community that will accept one or two elderly persons. They can't accept more than two because we will not certify them for more because it ceases then to be a personal kind of setting for the individual. Each retarded individual will be in the caseload of one of the assigned workers and be one of 80 to 100 active case responsibilities for one of our staff. They can't provide intensive supervision, but they can provide selective supervision, and some need little or no special attention while others need intense supervision.

Question: Are there any differences in commitment for children as compared with adults?

Answer: A person under twenty one is usually committed by his parents, or at least with parental consent and cooperation. As a practical matter, I can't think of many instances in which the question of commitment would come up at adult age. If the parents have died, the more likely approach would be to try to provide some

kind of court-appointed personal guardianship of the person or the estate, rather than to commit as retarded and institutionalize. Someone appointed by the court would help make decisions, handle money, handle earnings. The question of commitment is not necessary. If the services are needed, he is just as entitled to receive them without commitment as with it. The adult retardate might be living in one of the specialized congregate care facilities. There might be instances in which commitment would be necessary, but probably it would be specially tailored and carried out in connection with institutional planning.

Question: Do you foresee the day when there will not be some type of state operated institution?

Answer: I don't suppose the day will come when there will not be some type of institution, but I would hope that when the tired old physical plants wear out, they will be replaced by smaller, regional or local facilities or a more personal kind. With all the possibilities for financial support through combinations of resources such as Aid to the Disabled, I think other methods of helping the adult retardate remain in the local community can generally be found, except of course for the extreme cases - which are also of lower incidence, of course.

THE ROLE OF VOLUNTARY ASSOCIATION

Gerald Walsh
Executive Director
Minnesota Association for Retarded Children

The subject I was asked to speak about is the role of the volunteer agency. I think certainly we will want to talk about associations for retarded children and what they do in the field of mental retardation. First, though, I think we should take a look at voluntary agencies in general: why they are formed, how they are organized, what are their purposes. Dr. Blodgett said in introducing me that I had worked for associations for retarded children since 1955. Actually, I have been in voluntary association work of one kind or another for the past seventeen years, starting out on a half time basis while I was at the University of Minnesota. I have observed very carefully how voluntary groups have been organized. I was the first executive director of the Minneapolis and the Minnesota Associations for Retarded Children and therefore was able to observe the transition from the completely voluntary operation to one which hired a staff.

Most organizations, of course, start because there are people who are interested in some particular cause. In this case, it was mental retardation. It might start with just two or three people who feel that something needs to be done. They think, "There's an organization interested in the blind, or the deaf, or the crippled - why can't we pattern ourselves after them and have an organization?" - in this case, an association for retarded children. Then the organization will usually run along with a volunteer type of structure for a while, until it gets so complicated that they decide they have to be more structured. Probably they decide they are going to have to have dues. If they are going to have dues, they have to have a method of establishing dues; they have to decide what the membership year is. If they have dues, they have to have a treasurer. Soon they have started to have a fairly structured organization, operated on a voluntary basis with a board of directors and a membership. Then they ask themselves, "What should we do? What's the thing to push for first? They pick a project, appoint committees, and pretty soon another project comes along and they have three or four committees, and somebody asks them to do something else, and they have more committees and they reach the point where, as volunteers, they can't continue. They all have to make a living and therefore they say, "Maybe we should hire somebody to answer the telephone." This is the procedure that so many organizations have gone through. Often they don't even want a full-time person to answer the telephone. They want, perhaps a half-time person. In the case of the Minneapolis Association for Retarded Children, they hired a woman who was sixty-five years old and on social security. They had some office space at Powers Department Store. She answered the telephone, but the president of the organization was the admini-

strator; he told her what to do. After a while, this wasn't enough. They realized that they had to do more. If organizations on a voluntary health and welfare basis are going to do more, they are going to have to have money. So again, they look around and see what other people have done to raise money. Successful organizations have to raise funds. Probably the most recent organization to go through this process is the Cystic Fibrosis Association. There are others almost at this point - there is the Minnesota Association for Brain Injured. There is a newly formed Minnesota Association for the Handicapped that has just been organized. It seems that the agencies in the health and welfare field continue to multiply.

Usually, however, before an organization - certainly one in the field of mental retardation - gets to the point of hiring a staff, it has almost killed off two or three presidents. This happened in the case of our organization. Many people have neglected their work because they became so involved in the Association for Retarded Children. At this point, then, we have a membership which has a cause and a purpose. They have a budget, a part-time staff, an office, and from then on, the organization can continue to grow until it is as large as the National Foundation, for instance, which is one of the largest in the country. Or the organization can just move along on a half-on, half-off basis for years. Fortunately, our associations for retarded children have continued to develop and they have developed very quickly.

The second major point I would like to make is that when people form an organization, they have a responsibility to the public. They may be the members, but usually the money is coming from the public at large, so they can't just do anything they want with the money or spend it indiscriminately without keeping records or keeping track of how they do it. There are a number of things that are set up in an official way by state and federal agencies to control organizations. For one thing, if you are going to have a non-profit organization, you have to get a certificate of income tax exemption and you have to meet certain standards and have certain purposes. Annually, you have to file a report with the Internal Revenue Service; this is one thing you have to do. You also have to file a statement of income with the state. In Minnesota there is a charity registration law that requires any organization, any charitable organization or any organization that raises \$5,000 or more for a charitable purpose, has to register with the Secretary of State. These are on file for any citizen who wants to look at the information and decide whether or not this is an organization to which they would like to contribute their money. So this is in the area of financial responsibility.

As far as the operation of the board is concerned, direction is given by the board of directors. If the board wants to establish by-laws which have been accepted by the membership, the operating constitution needs to follow this very carefully - again, for the protection of everybody and to be sure that the organization will be truly

democratic. In our associations for retarded children, for instance, our by-laws provide that a nominating committee will be elected by the membership. This is protection to insure a democratic organization. It would be possible - all of you perhaps have belonged to organizations in which the president stands up and says, "Well, I want John and Jane and Betty to be a nominating committee and bring in a slate for the next meeting and we'll elect the officers," or they might say, "Jane, John and Betty, you go out in the other room and come back with some suggestions for officers for next year." And then you elect them immediately. With our organization, a nominating committee is elected, and reports its nominations a month before the election. All the members are notified of the election and there are rules and regulations set up to determine how people will be elected, who may be nominated from the floor and under what conditions. Again, this is part of carrying out the responsibility that organizations have, not only to the members but to the general public. The by-laws and constitution specify how money shall be spent, and for what purposes. The budget is drawn up and followed. Again, I imagine that many of you who are connected with organizations have had the experience of having someone in the audience, a member, stand up and say, "I move that we contribute \$50 for such and such a thing." Someone else says, "That's a good idea; I second it." Everybody votes yes, but this may not even be something that is provided for in the budget, it may be something you don't have any money to do, so you have to take it from something else that was in the budget. So, again, another responsibility of an organization is to have a budget. A budget goes hand in hand with program planning. You decide how you are going to spend your money for the year and you are deciding where you are going to put the efforts, talents, and energy of your organization. I think that people who work with voluntary agencies should know about the financial structure of the organization. You should know if it is carefully operated. I don't think anyone who has ever come to us to apply for a job has asked, "Do you have any money in the bank to pay me if you hire me?" It's possible that some organizations wouldn't have. There are many other basic things that could be said about organizations. I think, however, that maybe this is enough ground work. One thing you should remember is that even voluntary agencies formed for the same purpose will differ in the way they operate. A lot of this depends on the person who is the executive director, and on his talents, his abilities and his interests. The Minnesota Association for Retarded Children is very strong on legislation. I enjoy legislation. I think that our association does quite well in the field of legislation. On the other hand, if I had no interest in this and we didn't do well in it, chances are we would be taking this time and putting it into something else. At the last national convention, the executive director of the Michigan Association for Retarded Children gave a talk on how the executive director does his job. The way the executive director does his job has a great effect on the way the organization operates. He's the man who is there full time and really represents the organization even contrary to the wishes of the membership, if he wants to, because he is giving all of his time to it.

At the MARC convention, the Michigan executive read the following, it is about the six men who went to see the elephant, but all of them were blind. The first approached the elephant and happening to fall against his broad and sturdy side at once began to bawl that the elephant is very -like a wall. And then it goes on, with everybody having his own idea - the second feeling only the tail said the beast was like a rope; the third thought the tusk of the animal was like a spear. The trunk reminded the fourth of a snake; the leg was like the trees to the fifth, and so on. There is a modern tale that goes like this: There were six men of good intent, of sharp and clever mind; executives they are, and each was much inclined to think his specialty alone would benefit mankind. The first, a hearty noble soul, a salesman who they said, could sell a bag of feathers as a sack of molten lead. The teacher is the only thing the retarded need today, so number two came to the scene, but he didn't stay. The recreation worker ousted him with "Kids just need to play." A social worker then came forth with magic wand to wave, to prove that foster care and institutions saved. The fifth, a psychologist, made very clear his stance was on evaluation and regardless of the distance ran 50,000 IQ tests with federal assistance. Get an image, cried the newsman, let the public see the light. He was famous for his leaflets and his posters were a sight. He was television's darling and the press club's pure delight.

There really is no particular place where a person trains to become an executive director of an organization.

Looking more specifically at associations for retarded children, I can probably best illustrate by talking about our associations here in Minnesota and going back to what I said before about several people getting together and deciding to form an organization of some kind. In Minnesota groundwork for the first ARC chapter was laid at a picnic at Hammer School out in Wayzata - some of you have probably been there to visit. Rueben Lindh was the first president when the organization started in 1946. It grew, and in 1951 this organization plus other local chapters throughout the country and state organizations met in Minneapolis to form the National Association for Retarded Children. Then in 1951, the locals in Minnesota, recognizing that there were things they couldn't do individually and had to do collectively, formed the Minnesota Association for Retarded Children. It was several years later, 1955, that the first staff person, full-time executive was hired for the Minneapolis Association, and two years later by the Minnesota Association. The purposes of these organizations throughout the country are pretty much the same - to improve programs, conditions, everything that we can do to improve the lot and better the lives and development of the mentally retarded. This means, again, that you have many variations. Some of the organizations operate a lot of local services and feel that their only function is to operate a day activity center, or a camp, or a recreation program, or a combination of all of these things. They feel that they need to be the operating agency. There are others, which we in Minnesota tend to be like, which feel

that it is our job to show the need for these programs and perhaps to start them on a pilot basis and then get somebody else to operate them. I think the day activity centers in Minnesota are a good example of this. Operating the way that we have, fewer children are served at the very beginning, but more children are served a lot better half way along the line, because once an organization puts all of its energy into operating, say, a day care center, and puts all of its money into it, this is about as far as they go. They don't have any time left for public education and community planning and things of this nature.

I think all of you are quite familiar with associations for retarded children and realize that the local chapters especially do a lot of work with the parents. First, every organization - we have sixty four chapters in Minnesota - has a monthly meeting about nine times a year. We try to see that each of these monthly meetings is geared toward developing a better understanding of the problems of mental retardation, first on the part of the parents, and secondly on the part of other interested people in the community. If an organization did this, met once a month and had a good program of education, it would be worth continuing. Secondly, in many ways these parents help each other to understand problems of mental retardation. We do have individual situations where parents get together and exchange information. There are many professional people, too, who attend these meetings and help keep the parents on the right track, from time to time. Having the professional people involved in the association gives them social contacts with parents which carry over into their official contacts in the office. There are many parents who have their first contact with the county welfare department at an association meeting, and learn that the person from the department of welfare is interested and concerned and is willing to do something to help them. In association activity, also, public education is very important. We have a clipping service, which means we get clippings from all over the state of Minnesota about mental retardation. 99% of these clippings about mental retardation, both from an informative and general nature, are instigated by the local associations for retarded children. Speakers, quotations from speakers, such minor things as a notice of a meeting and sometimes just the fact that there are articles in the paper help other people to have a little better understanding and a little more realization that this isn't such a bad thing after all. I know that when we organized the chapter in Brainerd, a friend of mine came up and said she had seen the notice in the paper and was the meeting open to everybody, or was it just for parents - they probably didn't want any curiosity seekers. You see, this is the idea that people had that if you were the parent of a retarded child, you met in a darkened room and it was all right to meet with others who were parents, but nobody else should come in. So as we talk about this and publicize it, it makes it easier for the parents, it makes it easier for the child and neighbors who perhaps have not talked about the retarded child with the parents, do start to talk about it. We in the state association have carried on some major public information projects and I will go into those a little bit later

Going on and looking at the state association, again we have a great variety of activities. The state association, at this time of year, is working to promote a legislative program which was developed during the past two years. We have appointed committees, we have met to look at the needs and to make recommendations and we have put all of these together into a "Goals for Public Action" booklet which is really our legislative program. I have brought some copies of some of these things along. In our goals for public action we point out what we think are the needs for the state institutions - for more staff, for better buildings, the needs to improve special education and programs, the need to improve vocational rehabilitation, day activity centers, and other things. Drawing this up is easy enough, because anybody who has worked in this field a little while and has good common sense can sit down and make a pretty long list of needs. But then we work with other organizations in seeing that the needs are introduced into the legislature where action can be taken. The Minnesota Association for Retarded Children is a member of the Minnesota Council for Special Education, which is composed of people with interest in the deaf, the blind, the crippled, and so on. In working with the legislature, we spend a lot of time at the capitol. They call it "lobbying" although we don't use that word because we are a non-profit organization and are restricted in the amount of lobbying we can do. We have made a number of special studies, pointing out these problems, and I brought along some samples of these for you to look at. For instance, on September 9 and 10 of this year we had a staff person at each of the three major institutions for the mentally retarded and we interviewed each charge aide in each building in each of the major institutions at Faribault, Cambridge, and Brainerd. We wanted to take a picture of the actual on-duty staff in one twenty-four hour period and be able to relate, building by building, the problems of staff there and be able to say, for instance, that a certain building has only one aide on duty at night for 177 patients, so that when we go to the legislature, we can say this is what our study shows; we know this to be a fact. We know also that we can be effective doing this whereas we don't get any place appealing to the legislators on an emotional basis, saying "retarded children can be helped" and they look at these poor little children, for whom something should be done. This doesn't do anything for most legislators - not because they are hard-hearted, but they have a lot of people using this approach. The problem of legislation is not just one of lobbying over there, it is one of gathering the facts and information first. This study covering the Minnesota institutions for the mentally retarded was very inclusive. We can tell you exactly how many people were on duty at any particular time. The reason we want to be so specific about this, on this particular twenty-four hour period, is that institutions have a certain staffing allocation - people have vacations, sick leave, and days off - Saturdays, Sundays, holidays - so that the number of staff assigned does not relate the whole story. We also asked the aides in the building to tell us what their biggest problem was. For instance, one says inadequate facilities - a three-story building with two playrooms on separate floors with only seven toilets and one shower and one tub for

71 patients. We asked her what would she suggest as a solution and she said more help, technicians, and improved facilities. So this is the basis for our work with the legislature, to give them information and facts. To do this, we have on our staff in the Minnesota Association a research person who writes this material up and is the coordinator of the research project. We are using this in four different ways. There is the study itself, which has the complete information, and secondly, we have done an abstract - and we have an abstract of the abstract. The one thing that we have a product of - not a finished product, because I went by the printers this afternoon and picked this up and we had to hand-trim it by scissors - but we took the information from the study and used it to produce this brochure, A Major Minnesota Problem. By using these colors (maroon and gold) people are at least going to open it to find out what is wrong with the Minnesota football team. Hopefully, they will go beyond that, and once they are into it, we hope they will continue and this will be a help to us, as we try to get more staff for the institutions. We have utilized in this a quotation from Governor Rolvaag in which he said that the fact that "the institutions for the mentally retarded have been seriously neglected and points out the lack of staffing is absolutely unbelievable." We have utilized quotations from this report - for instance, one in which a psychiatric technician says, "we need more personnel so as to be able to work more closely with the patients, thereby teaching them to learn to live with one another and help prepare them for the possibility of living outside of" the institution." We have used a quotation from a mother in which she says, "Then, too, she beats her head on the floor until it bleeds, if no one stops her. There was no one to stop her and the sore caused by her banging was infected." So what we are trying to do is not only break through people's rationalizations, but once we have broken through, then to try to give them reasons why they should do something to help solve this problem. This is the reason that in the middle, for instance, we say that just being able to feed oneself gives great personal satisfaction, and the quotation from the psychiatric technician who says that "many more of them could be taught self help and toilet training, but this is impossible with the number of technicians on duty." It's a matter of trying to have the proper balance between the problem and the solutions, and the hopefulness that will make people spend more money in taxes. This is an example of something that we think will be very useful. We haven't learned how to do this as an association in one year or two years - we have been learning constantly since we started our legislative program, and we made some very serious mistakes to begin with. For instance, we used to talk in terms of the staffing ratio being the total number of patients to the total number of staff. On that basis, Faribault would have one employee for each four patients. That sounds pretty good until you start actually figuring out what happens when you take away the painters, the typists, and so on. These are some of the kinds of things that we are doing in connection with legislation. We have an active legislative committee; we have two parents, young, attractive parents who come over to the legislature and help work with the legislators, and we have special

hearings where they bring other people in to work with us. In the area of public education, I think we have gone fairly far - perhaps not as far as some states have gone - but we did, about a year ago, conduct a statewide evaluation of the public's attitude about mental retardation and the degree of their knowledge about mental retardation. We did this on a state-wide sample, where 990 people were individually interviewed. The same sample was used for the Minnesota poll. We came up with a very complete study. I have an abstract of that and I brought along copies of that for you entitled Public Impressions of the Mentally Retarded. I can show you samples of the kinds of things that can be done and are being done by an organization. We, of course, put out Newsletters and special brochures and things like this. This fall, Lucy Cook, who does the publicity for the Minneapolis Association, talked to WCCO radio-television and maybe this series of, I think, eighteen ten-minute T.V. programs on mental retardation in this area - day activity centers, research, the whole thing - will be shown. Again, this is something the associations are doing.

I think another area of great importance is not only the work we do at the legislature but the work we do with the official agencies of health, education, and welfare. In many cases, we reinforce and support their programs. We have a governmental affairs chairman for each of the 64 chapters who are in touch with the legislators before the legislature starts. They write to them, they visit with them when they are home on weekends. Two special things we are doing this year are new. Tomorrow, I mentioned, we're having a bus tour - One to Fari-bault and one to Cambridge. We have invited representatives of business, politic, civic, religious organizations at the state level to attend this tour to learn first hand what some of the problems are. Then on February 18th, we are having legislative day and have invited all of the legislators to have lunch with us at a church near the capitol and again, having our association members come and bring with them a representative of the Mrs. Jaycees or the Jaycees or some other organization that has mental retardation as a program. We try to get involved quite a bit in coordinating the activities in mental retardation, always realizing that if somebody else will do it, we are better off. There are several coordinating bodies in Minnesota that we work with. There is the inter-agency committee on mental retardation that is made up of representatives of the official department and our associations for retarded children. This group meets about every other month to exchange information, programs and projects. We have representatives serving on quite a few different groups - for instance, we have a representative serving on the four-county project on mental retardation, which is at Owatonna, where they have a special group of professional people who work in the community, doing diagnostic work and encouraging the community to offer more services. We have a representative on the day activity center advisory committee at the state level of the Department of Welfare. There are quite a few groups like this; I haven't made a list of all of them. We do a great deal from the state association level, working with the local chapters, giving them help, consultation, and advice, and of course

also from the state level, trying to organize the associations where there are not associations at the present time. I don't know if it's good or bad - I think it's good - but Minnesota has the largest state association staff in the country. We have an assistant executive director in Dick Rothmund, Ralph Larson who is our new camping and recreation director, three field representatives, a director of public information, a half time research person, plus the secretaries, book-keeper, and so on. But the reason, again, why we are able to have this kind of staff and this kind of program goes back to something I said before - our feeling that if we can get other people to do these things, we are better off. So we put more money into staff and program at this level rather than into the direct services and I think this is paying off. For instance, the governor is recommending \$522,000 for state matching funds for the day activity centers. Now if we put all of our money into the activity centers, it wouldn't amount to a great deal - probably \$100,000 as compared to this \$522,000. We would have had the centers operating sooner, but instead, we put our energy toward development of a state program and into legislation, so at this point we are farther ahead.

All of these organizations, associations for retarded children, are interrelated in that the locals belong to the state association and also to the national association. They all have independent boards, so any of them can do what they want, within the certain limitations and rules which have been agreed to by all of them. We call on the national association for quite a few services and information and they have consultants in major fields of recreation, institutions, education, sheltered workshops. They are hiring a research director who will help coordinate the national association's research. We call them in for specific national information, exchange information between associations through them and the national association carries on a legislative program in Washington and of course works very closely on the new federal legislation.

I mentioned before that we are quite a bit like other organizations that you might be familiar with - heart, cancer, crippled children, groups like this - except that none of these organizations has the local participation that we have and very few of them involve the people who are affected by the problem the way we do. One of the reasons that our program has been successful is that the parents who are so deeply affected by this become involved so that besides doing things that will help their children, the parents have an outlet for their energies. It helps to avoid the frustration of having a problem that you can't do anything about. Parents who feel very strongly put a great deal of time into this program. Not everybody feels this same need to do something. Some people just sit and do nothing, or sit and suffer, but some people put in 10, 15, 20 hours a week as a volunteer in a program and this helps to improve the program a great deal. It also helps to make them feel better.

Now I certainly haven't mentioned everything about our association or organizations. I would hope that you have some questions. Maybe some of you would like to know if there is any justification for an organization like this even to exist - why can't the government do all these things that we are talking about, money for programs and so on. Harriet, do you want to take some questions now?

Blodgett: Would you talk a little about the attitude of MARC toward contributions to research areas?

I think this is a good area and we should spend a little time on this. We have the largest program and the largest staff in the country. We originally started by having our own independent campaign in Minneapolis, St. Paul, and throughout the state. From this campaign the money raised, after expenses, 15% across the board goes for research. This is research at the national level, medical research, but then also research in Minnesota. For instance, we are financing a project at the Dight Institute which has to do with determining the relationship of finger prints and palm prints to mental retardation. This is one project that we have helped support. We have for many years given money to the Faribault State School and Hospital in connection with their studies on phenylketonuria. There are other projects along this line. We have a very able research committee that decides how to spend this money. Harriet is on it, and Dr. Jenson, Dr. Reynolds, Dr. Sheldon Reed and a number of other people. Again, this reflects the fact that we feel we have to push forward in many different ways. Our state ARC receives 35% of the funds collected, which is a great deal in comparison with any other state. But again, I think we have been able to do a great deal because of this. We have always been one of the top supporters not only in research on the national level, but one of the very top supporters of NARC in total. We are given an annual quota and this year it is over \$25,000. Then, the local associations can receive varying amounts of the total we receive from our campaign from United Funds, depending on their program, up to 35%, but they can raise other money that they don't have to give to us at all. I said that originally we conducted our own campaign every place, but now we are in about 400 United Funds of all sizes in the state and still carry on our own campaign where there is not a United Fund, although we are not happy with the amount they are willing to give us.

I expect you have a lot more questions. I brought along some other materials - a Minnesota Association brochure and some other brochures, samples of things we produce as an organization for our local chapters. This is one that we are just putting together today - a survey of daytime activity centers for the mentally retarded in Minnesota. I talked about a staffing study to determine what is happening in staffing. Last year and this year we have also done a survey of the daytime activity centers. Our survey points out a number of interesting things that will help us get the \$522,000. For instance, the directors of these centers reported that many of these children

were kept at home because there was a center. There is no real way of evaluating this unless you went out and checked with each individual person. Secondly, and this we did check out very carefully, eleven people who were in the centers for post-school retarded were placed on full or part-time jobs. This is something we didn't expect to happen. I think it was four people who were in an institution at one time and now in the community in a daycare activity center. There are other facts of this kind that will be helpful to us. We list the additional problems that the people in the centers have, besides mental retardation. Most of them, 46 out of the total, I think, of 323 that we surveyed, have speech defects. I think this should probably be higher, Twelve have visual defects, eleven cerebral palsy, and so on. These again" are the kinds of things we use when we go to the legislature. Another thing that we can do is stimulate governmental action. We went to Governor Anderson and asked him if he would appoint a special advisory committee on mental retardation, which he did. Later, after this report which we pulled together with out staff and had printed, this was extremely valuable. Some of the other things are minor in nature, having to do with a publicity manual, information on how to organize chapters, and things like this.

Blodgett: Why don't you tell them a little bit about how you get chapters started, and how many nights you are out on the road?

Well, not as much any more because we have more staff. First, we do not go out into a community and organize a chapter. We wait until there is community interest and the parents and the community feel the need for this kind of organization. I think now there are maybe ten, at the most, counties that don't have chapters. I know we could go out next month and for an organization in every single one of these counties, if we wanted to. But it has been our experience that when it's done this way, they don't last - they don't have the energy or vitality that they should. So we wait until parents become interested, and then go out when we have five or six people and have a pre-organization meeting, talk with them, tell them how the chapters operate, what they do, and then ask them if they think this is the kind of organization they would like to have in their county. If they say yes, we then work with this group, give them certain specific assignments such as publicity, lining up a hall, refreshments, coffee, and so on. We line up a speaker and then we have an organization meeting where we invite as many parents as we can get, professional people and so on, explain again what the organization does, and again ask if the people feel this is the kind of organization they want. At the pre-organization meeting, in practically every instance, leadership emerges - somebody who appears to be a natural leader, and this person gets the job right away. Then by the time of the organization meeting, we usually know enough about people so that we can appoint the preliminary officers to start with on a temporary basis, and then they adopt their by-laws and have their election. We work with them closely for three or four months, furnishing their speakers and trying to get them off to a broad approach to mental retardation to learn about institutions, special education,

community services, department of welfare, public health nurses, and all of these people. We have very few associations that have failed, but occasionally they do.

We have for the last three years or so been studying whether or not we should establish at the state level a residential camp for retarded children. In our policy manual, we say that we will not operate any direct services at the state level for retarded children, unless nobody else will do it and it seems that we should do it. We determined that a camping program is something the government won't operate and to be successful it has to be operated on a state level. After considerable study, we purchased a resort which is one of Minnesota's best resorts. It has 75 acres, 31 buildings, 600 feet of lakeshore and is all practically ready to go, as soon as Ralph gets some of the kinks out of planning the programming. Starting on June 20th, we will have four two-week camper sessions for retarded children from all over the state. We will have twenty junior counselors, ten senior counselors, a doctor who will be there full time (we will furnish him a cottage and vacation for this service) and at least one nurse. We hired a kitchen and dining room director, who is a home economics teacher at a school; we will have water front people, a recreational director, nature director. In the latter part of the season we plan to have three one-week periods for family camping, where families can come if their child is unable to function independently at the resident camp. They'll come with the normal children and the retarded child and we will have a special program for both of these groups. Throughout the year, we hope to have groups from state institutions who can go there for vacations or weekends. Hopefully, we will be able to develop an area where retarded Boy Scout troops can camp out and possibly a tent camp area where families who don't want to come and live in a cabin can use a tent area. This is going to be a good program and very interesting to watch.

Question about matching funds:

Answer: In 1963, the state legislature appropriated \$155,000 to match local funds. We had asked for \$220,000. The state will match up to 50% of the local fund. We encourage the counties to contribute - the county government - because this is the best way to set up the centers on a regular independent basis and also encourage that they be established as separate organizations; the day activity center has its own board and it's incorporated.

The law provides that the commissioner of welfare should establish standards. Standards are established probably in two ways. First there is the child welfare division that has the responsibility for setting standards for all child caring agencies. They pretty much apply to standards for normal children in day activity centers, but then the medical division, under the section on mental deficiency, is establishing regulations for operation of day activity centers, regarding staff

and other things. There is some overlap here, because child welfare also establishes its standards for program.

Question about the poster boy:

Answer: Yes, Dickie Bach is this year. They had submitted his name as a national poster boy - there is each year a national poster boy in connection with national retarded children's week in November. Anybody can submit a suggestion for this. In Minnesota, we have had a state level poster boy for about the last four or five years. It helps us carry on our fund raising and public education program.

Question: What are you going to do when everything is taken care of? When you have all the money you need, and all the day centers you need?

Answer: Well, frankly we haven't had time to think about this yet.

Comment: Well, the kinds of children change too, and no one generation can understand all about this too well, because nobody's professional life is that long, but you can get some idea about it from looking at the historical material about retardation. I think it is quite clear that we are seeing different kinds now. Some of the babies that were saved that used to die are presenting us with some more complicated kinds of retarded children that we used to see and this makes a difference in programming. Just looking at the diagnostic problems with the overlap of sensory handicap, organic damage, personality defects as well as intellectual defects - some of these didn't come under retardation as it was interpreted twenty years ago, but they do now. Even in public school classes, we see some emotionally disturbed children who have specific learning disabilities and yet are not technically retarded in terms of test score - this may be a kind of warning of some things we will see in the future...retardation is a pretty big umbrella.

CONCEPTS OF PROGRAM PLANNING FOR DAY ACTIVITY CENTERS

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The Sheltering Arms

(This paper was presented at the Institute for Day Activity Centers held in Minneapolis in May, 1965, and is included in the lecture series collection at the request of the trainees.)

Any planning for any kind of program must begin with definition of the goals of the program. These, in turn, must be shaped by the limitations and capabilities of the children being served. These, in turn, are related to age ranges and stages of maturity of the individuals in the group.

Most daytime activity centers have developed their programs around visible needs in their own communities, and we see different centers serving different groups, depending on what else had previously been available in their communities and what seemed to be the greatest unmet needs. We can define several groups which are being served in different centers. At the preschool age range, we find young trainable retarded children and some young children who may be educable in ability but who have some special problems or multiple handicaps. At school ages, we find some sub-trainables who are not eligible for school programs and some trainable and educable children who, for various reasons, can't adapt to public school programs. At post-school ages, we find trainables and some educables who can't adapt to other ways of living in and participating in the community. In other words, much of our population consists of "can't adapt." We would probably find the bulk of our population to be below IQ 50, but there will be quite a few exceptions who are legitimately included in day activity programs because this is the place they can function. Some of them will be there only temporarily, and will be able to move out into different settings as they make gains in maturity or behavior control.

When we think in terms of the purposes and goals of our programs, I would want to give first place to the mental health values which concern us. Mental health is a composite of many qualities; we think of such things as release of tension, building self-confidence, providing success experiences, a sense of security, relaxation and joy in living, acceptable emotional outlets, building positive self-concepts, developing frustration tolerance, having comfortable relationships with other people. This last one merges into social skills. We would add personal freedom and independence, acceptance of limits and authority, communication skills and listening skills, consideration of others - their feelings, their rights, and their property, cooperation with others, reliability and

trustworthiness, fair play and sportsmanship, health and safety. In the motor area, we are concerned with motor coordination, large and fine muscle skills, eye-hand coordination. We would list also individual interests and abilities, ways of self-expression in all areas - artistic, verbal, physical, dramatic. Many of these add up to skills which have functional application for daily living. We are interested in development of judgment, even though this may be based largely on habit, awareness of the environment, skills for self-preservation, self-help and personal independence, some awareness of time concepts at least on an associative basis, self-maintenance, recreation, some economic contribution. In the intellectual area, we are concerned with functional oral vocabulary, ability to communicate, recognition of safety words and other useful word recognition, speech and language skills, visual and auditory discriminations. For those for whom it can be meaningful, we are interested in academic learning.

When we begin to translate purposes and goals into program activities, we identify some different basic needs at different age levels. For our young children, emphasis will be on the motor areas, basic habits, and self-help skills. For the middle childhood years, from seven or eight up to early adolescence, emphasis will move to social and skill areas. For our older groups, there will be continuing emphasis on social and skill areas, with added stress on self-respect, reliability, and contributions to their own living.

We can make some statements about principles of program planning. First of all, no standard curriculum can be set up to fit every group. It is the task of the teacher-person, whatever his specific title, to adapt the general principles into the specifics for his one group. To do this, he needs to be clear about the goals and purposes and he needs to be skillful in using activities to contribute to these goals. For example, perhaps learning to take off and hang up outdoor clothing does not appear on the daily schedule, or perhaps it does, but certainly for young trainables this experience is highly important to self-responsibility and may well consume twenty minutes at each end of the day. Part of the good teacher's skill at making this a learning experience is that each child is motivated to effort-making because he wants to get ready to do something else - perhaps something which is merely formally on the program and is labelled "curriculum."

There are some negative principles, things which we know don't work and won't work. Among these undesirables: Too much "workbook" approach, too much academic emphasis; too rigid a program, which stifles spontaneous interest; too punitive an attitude on the part of the teacher; too much talking; too much stress on fine motor skills. Fortunately, we also know some positive principles to replace the negatives. One important one is to make use of the immediacy of interest, take advantage of the moment. One of our teachers developed a whole project around weed when some tree

trimming was being done on our grounds and the children were fascinated by the equipment and the procedures. Among other positive principles, we know that children generally like to do what other children are doing and like to be with other children. They like to have some freedom from criticism and from constant direction. They like the security of some familiar routines, knowing what is going to happen when, and they like some novelty, some change, and some freedom.

Having set forth gone principles, the next question concerns how we put them into practice. One good way is to plan a wide range of activities around a central theme. In the fall, the weather theme is useful - leaves falling, birds departing, animals preparing for winter. Songs, painting, games, rhythms lend themselves to the theme. There are all sorts of health projects - a good breakfast project can include discussions, pictures, scrapbook making, cereal cooking and eating, which leads to table setting, manners, dish washing. Since young retarded children are apt to be self-centered, an "All About Me" project has special appeal, with the children finding pictures to represent their house, their parents, brothers, sisters, and pets. It is fairly impressive when a youngster of IQ 35 insists on adding a moustache to the picture to represent his father, or finding a picture of a lady with glasses because his mother wears glasses. All special events and experiences and many movies can be enriched by preparation in advance and follow-up later. A trip to the circus is more than just one day as far as program is concerned; it means a couple of weeks of focus on animals ahead of time plus reviews and dramatic play afterwards, plus stories, songs, games, and "play-pretend" all along the way. Special visitors have obvious tie-ins with community services. The policeman, the fireman, and all the various "fix-it" repairmen have program possibilities. This will often mean scrapping the planned activity to take advantage of the immediacy of interest principle. When the plumber comes to fix the sink, a whole new project can unfold.

For the older groups, again our concern needs to be with their real world and with the provision of real experiences of doing - cooking, cleaning, fixing, creating, taking advantage of some of the adolescent traits of competing and teasing-grouping. Self-care has a personal focus at these ages, and tasks must be useful and meaningful. Most programs for older retardates fill an important place for grooming skills and attention to personal appearance. Helping develop good leisure time interests which can be carried over into adult years is another useful focus. For younger children, there needs to be some attention to a balancing or alternating of more active pursuits with more passive program content. For older children, time spans can be longer, but they still need some outlets of free time. For older children, there needs to be some heavier emphasis on socially acceptable behavior and on acquisition of independence in areas where this is possible. The

central theme, whatever it is, should have some interest value and meaning, and should offer new experiences plus reinforcement of social living skills.

Programs for younger children will need to be shaped not only around their intellectual level but also around their particular emotional problems. A good school experience can help to minimize these problems for later program planning. Beginning day activity pupils may present some special emotional problems. I am indebted to Mrs. Winifred Johnson, who teaches our youngest trainable group, for some of the following descriptions of some of these special problems.

Beginners should have very few rules which are punishable. Two we use for our beginners are: being rough with anyone's glasses, and climbing on the fire escapes. These are "spankable" offenses. Other rules are simple and children are just reminded over and over again, not punished. Some of the special emotional problems we have seen are these:

The hostile, frightened child. He may be directly resistive or attacking, or he may be "frozen" and non-participating in behavior. The essential teacher behavior is friendship, helping the child to understand that you are his friend and you like him. Do things with him - "Let's go get some paper now;" need his help - "Will you hold this for me?" Have interesting activities that he can observe and join in when the spirit moves him - dramatic dress-up play, stories, active games. Encourage him to try new things, very simple ones at first so there is little chance of failure. Give much praise for success, but, above all, be his friend.

The hostile, aggressive child. Early in the game, he can play as he chooses, but he is not allowed to hurt other children. He can spill water, throw sand, tip over chairs, kick furniture, throw toys. He will begin to stop this when he is not noticed especially. Then you can try to direct the activity into active play - beats in the water, washing dishes or doll clothing, making roads or cakes in the sand. This child does need to be watched so he will not victimize others. Isolation is the main discipline used. Other children will resent his behavior and will tell him so. When needed, discipline should be firm and followed through. He will finally want his teacher's approval and his classmates' approval, and this will help him put on the controls.

The hyperactive child. At first he is allowed to run, to jump, and to yell. Other children will need to be kept out of his way for a time. Then the energy can perhaps be directed into active games - races, bowling, skating. At group times, this child will have to be put back in his chair over and over again, firmly, with no hint of punishment. Gradually the group turns on him

because he is so disruptive, and this social pressure also helps him gain control. The skillful teacher will try to find something he especially likes to do and to use this as a bridge. When you can, try to share a favorite activity with him - it might be just talking, or a particular game or story he likes.

' The withdrawn child. This is the child who may take weeks to get off his coat or move from the door, or start to talk or eat. At first, make only occasional verbal contact - a smile, or use of his name when talking to the group. Physical contact must also be very gentle; do not try to force the child out of the safety area he has selected. Each day you can add a little more verbal and physical contact, but it is a slow process. Don't rush it. Other children help with this kind of problem.

The perseverative loner. Perhaps this is the hardest one to see progress with. Often it seems that you take two steps forward and then one step back. Sometimes he must be allowed extra privileges, such as leaving the group, or having things of his own - a collection, or a certain chair. Try to find his interest and develop it. He probably can't tolerate too much pressure, but he needs a very firm, kind hand at all times.

The immature. Help with new experiences and build up confidence in self-help skills - bathroom, hand washing, coat off and on. This child can use a lot of praise. This situation, too, is one in which you very much need home cooperation. Often parents do not realize how much they have babied this child and done everything for him all along the line.

The child with poor coordination and poor motor control. One of the teacher's problems here is to find material he can successfully achieve with - big blocks, sand play, big balls, painting with big brushes. This child also needs much praise and often needs help to prevent total failure and frustration and loss of interest in trying.

Multiple handicaps. The teacher's difficult job here is to find activities that include him in the group, and this job would vary, of course, with the kinds of handicaps. With young blind retarded children, there are many possibilities in music, stories, balls, blocks, marching, circle games, and "listening walks" when everyone listens for the wind, cars, birds, planes. Many experiences with textures - hard, soft, rough, smooth - and with temperatures - cold, cool, warm, hot - and generally exploration by touch are important. Other children are generally helpful and considerate, in our experience.

The curious, active child. He needs plenty of time to explore the room and the equipment; he generally wants to see the whole situation and have his questions answered. This kind of child can always find his own activities, but will need some help and some steering to make the best use of them.

If children in general are not forced to participate in a group activity, but rather are allowed to choose some individual activities, they will gravitate toward the group at their own pace. A few children who are unusually rigid may occasionally need forcing, but this can have some unfortunate results and it is well to take lots of time to make this decision. If a few children are involved in an activity, some others will generally come and join then. Others who do not join will be actively observing and will be interested, and will be learning. At the older ages, it is important that tasks be real. Washing doll dishes is no longer appropriate and besides, it looks ridiculous. Real projects which are legitimately a part of the grown-up world - arts, crafts, recreation, home economics, woodwork, ceramics - take on additional meaning by reason of their realness.

The teacher's real, innermost beliefs and attitudes toward children are of crucial significance. If the teacher is genuinely considerate, genuinely concerned with individual children's comfortableness and feeling of well being, this has some gradual carryover through media of non-verbal communication to the children themselves. The teacher, in short, is at the heart of the program. It is her philosophy of child development, the needs of children, and the capacities of children, even when these are very limited, which will find expression in the activities she plans and carries out.

DAYTIME ACTIVITY CENTERS FOR MENTAL RETARDATION

James Gavenda
Director
Hennepin County Daytime Activity Center

Day Centers for mentally retarded children in Minnesota date back to 1954. The Minneapolis Association for Retarded Children (MARC), acting upon a community survey that determined a need for such a service, sponsored a day care program at the Waite Neighborhood House. This program began in June 1954 with a population of four children. Over a ten year period the program grew to thirty children, in three groups, with an age range from four to eleven years. The waiting list often approached double the number being served. When it became apparent that the facilities were inadequate, MARC encouraged several community agencies to assume the responsibility for the program. The agencies contacted all agreed that such a program was desirable and should be expanded. However, for good reasons and many, none was willing to assume the responsibility to administer a day service for retarded children.

On the basis of a study completed in 1961 by a Health and Welfare Council Committee, MARC agreed to administer the Daytime Activity Programs for the mentally retarded in Hennepin County, and also to expand the then present center to more than twice the present enrollment. Funds for the operation of a Daytime Activity program were made available from four major sources: The Hennepin County Welfare Department, the Minnesota State Department of Public Welfare (made available by legislation of 1961 and 1963), United Fund, and by parent fees. On January 1, 1964, MARC assumed the responsibility of administration and supervision of the Hennepin County Daytime Activity Center (DTAC). The DTAC is located at 1701 Oak Park Avenue North, Minneapolis, Minnesota.

Prior to the 1963 legislative act, day care centers for the mentally retarded had three primary goals: 1) Provide an opportunity for retarded children to develop socially and educationally to their maximum potential in a group setting; 2) Provide parents of retarded children relief from the constant care and supervision necessary; 3) Provide counseling services for the parents of retarded children.

With the change in philosophy from day care to daytime activities in a community setting, the goals also changed. Although the Hennepin County DTAC differs from other centers in regard to size of the population, ages served, and status of physical facilities available to their use, all DTACs in Minnesota share to a large degree, the same goals. They are socialization skills, self-care skills, pre-vocational skills, parent services, referral services, and long-term non-clinical diagnostic services.

Socialization skills include experience in a group setting which necessitates learning to share, take turns, respect the rights of others, and respond positively to an authority figure. Success or failure to function in the community is directly related to proficiency in these areas. Also included in the area of social skills is exposing the retarded child to successes and failures and assisting him in dealing with both.

Self-care skills vary with the amount of experience and the age of the group. With the younger children, the very basic self-care skills such as feeding, washing, and dressing are stressed. The older groups would work at a more sophisticated level on such things as the effective use of deodorants, shining shoes, washing and ironing clothing - to mention just a few.

Pre-vocational skills and activities are more particularly directed to our teen-agers. The emphasis is on the "pre" in that we would not train them for one specific job. We would be working to develop good work habits and attitudes necessary to function successfully in the world of work. Emphasis is placed on the practical skills that would facilitate an easier adjustment to a work setting. Such activities as the use of public transportation, familiarization with money and its use, and practical home economics activities are just a few of the areas stressed.

Parent services would include both parent relief and parent education. The former refers to a limited number of children being served primarily to provide some relief at home. Placement in these cases is usually short term and emphasis is placed upon training in the very basic self-care skills. The Legislative Act creating Daytime Activity Centers specifies that parent education be provided. This requirement is fulfilled in a variety of ways. There is a monthly parent meeting at the Center on the first Wednesday of each month. Usually there is a guest speaker and time is provided for parents to speak with the director, public health nurse and the individual instructor of their child. Attendance at parent meetings is required and failure on the part of any parent to attend two consecutive meetings without valid excuse will place in jeopardy the stay of their child at the Center. Cooperation between the home and Center is essential for maximum effectiveness in working with the children. In addition to parent meetings, the director and the public health nurse try to have conferences with each family during the program year. Progress reports are made out on each child two or three times a year. The month of February is set aside as the time for individual parent-instructor conferences to discuss these reports. While the parent education services mentioned are provided at specified times, the entire staff of the Center is available at any time for questions or conferences at the request of parents.

Referral services are continuous. While a Daytime Activity Center could conceivably be the starting point in services to the retarded child, it should not be the stopping point. The Activity Center should represent one service in the continuum of services available to the retarded. This being the case, awareness of new and perhaps more appropriate services is a must for any Center that wishes to serve the retarded most effectively. During the course of a year a Center should be continually evaluating children as to their suitability for placement in public school programs, vocational training centers and any other service available.

Long term non-clinical diagnostic service is accomplished by extensive and continuous observation and evaluation of each child enrolled at the Center. Information so obtained will lend itself to more accurate prediction of what can be expected of a particular child and assist in finding suitable placement as his needs change.

The enabling legislation of 1963 also set basic requirements as to the classification of retarded that could be served by a state funded DTAC. Within the legislated framework, the following were to be provided service: any person who is diagnosed as retarded; school age retarded children who are neither educable or trainable; mentally retarded children and adults who are unable to attend school because of chronological age and/or are unable to engage independently in ordinary community services. Any specific service limitations are primarily determined by the State Department of Standards and Licensing.

A major problem in many, if not all, DTACs is the obtaining of adequately trained and experienced staff personnel to carry out effective programming efficiently. The state's basic requirement is that the director of a DTAC possess a bachelor's degree with training and experience in the area of education, child development, special education, parent counseling or psychology. It is, of course, desirable to have as many trained and experienced personnel as there are positions available within a particular DTAC. Basic qualifications of instructional personnel that are desirable are as follows: Possess the ability to relate to children in a positive manner; be able to understand children and their problems - but not across the board acceptance of deviant behavior; possess imagination and enthusiasm; be able to work for extended periods of time without experiencing guilt feeling about a lack of obvious and immediate success; be able to accept the mentally retarded child regardless of superficial happenings - this does not imply never showing disfavor with activities. Whether or not a college degree is required depends, in practice, on the size of the Center and how many instructional staff members are employed.

In conclusion, DTACs in Minnesota are varied in their physical size, numbers served, and classification of retarded being provided service. The actual programming may be different; however, the

major goals should be similar throughout the state. In addition to tax sources for operational funding, many centers are supported by private service organizations such as the Mrs. Jaycee's, The Elks, Civitan Clubs, VFW and American Legion organizations, as well as individual contributors.

The ultimate goal of a DTAC should not be to become a substitute service for schools and/or institutions. The purpose of any DTAC should be to provide services within a community to the mentally retarded who can benefit from such a program.

SHELTERED WORKSHOPS

Mervin Healy
Director
Opportunity Workshop

We are in our twelfth year of serving the mentally retarded young adults. Opportunity Workshop began in 1953 when we became a legal agency. Its beginning was in a five room house on Penn Avenue with fifteen young adults, strictly as a sheltered workshop. During the first few years there was no training and evaluation. This program was not developed until some time later. The first job they did was sorting and rolling newspapers; this has been a job that has been done in many workshops as a starter around the country. The program went along for several years as a terminal sheltered workshop.

You might like a little background as to how it got started. Through the initiative of half a dozen families whose retarded adolescents were soon to leave the Home Study School, a survey was made by the Family and Child Welfare Division of the Community Welfare Council. This survey pointed up two conclusions; the community lacked a meaningful post-school program for those retarded who could not easily be absorbed into the labor force, and there was an intense interest on the part of parents in employment for their retarded adolescents. These parents were convinced that their retarded young people could be productive workers and need not sit at home and deteriorate. The Community Welfare Council recommended that a sheltered workshop be established. A Board of Directors was organized, drawing membership from the ministry, law, and school administration as well as parents of retarded young people. The corporation was approved in 1953. Help was given by the staff of the Community Welfare Council, and civic-minded individuals and service groups became interested. Two families without retarded children purchased a house in which to begin the program. The Junior League of Minneapolis made a contribution toward the salary of a director; and the Southwest and Suburban Kiwanis Club gave financial support and labor to the operating costs and remodeling of the building. A director was hired, intake procedure was established, a fund raising campaign was conducted, and Opportunity Workshop opened on November 3, 1953.

For the first four years, Opportunity Workshop operated primarily a sheltered workshop. The training inherent in the program was intended as preparation for sheltered employment, and the clients were not expected to become capable of competitive employment. However, a few clients began to show potential for such employment and the State Division of Vocational Rehabilitation referred two clients for training. Consequently, we began to make a distinction between training and sheltered employment in January,

1958. By this time, enrollment had increased from fifteen to thirty, and the house was now far too small for comfort. A concrete block, industrial type building was constructed on the rear of the lot, and the house was retained for office space. Again, we soon outgrew the space and in 1960, the house was moved and a two-floor addition to the concrete building was made. It was also in 1960 that Opportunity Workshop joined the United Fund organization. Our most recent move has just taken place; our new facility is located on one and one-half acres of land out near the freeway at 512 West 78th Street. Plans are under way for an addition to be built which will provide 24,300 square feet of space. This will enable us to serve from 180 to 200 clients, as compared to the 100 we are now serving. Over the years of our operation, the annual budget has also increased, from \$8500 in 1953-54 to \$160,000 in 1963-64 and a projected \$170,000 for this year.

Our board members, twenty-three of them, set policy and are pretty much representative of the whole community. I think there are about five professional people, about five housewives, five business people, and then a clergyman, an attorney, an accountant. Currently we have a staff of eleven, which breaks down like this: We have a program coordinator - psychologist position, a dual position which happens to be vacant right now. This is a hard position to fill because it calls for someone interested in administration with some experience in this area who is also a certified psychologist. There are perhaps six or eight people in the Twin Cities area who would fit the position, and none of these are interested or available. I think we are going to have to break this position down into two separate jobs. We also have a vocational counselor, 2 1/2 work evaluators, the workshop supervisor, the shop foreman, a full time contract procurement director who spends all his time seeking contracts for our people to do, a full time placement director who looks for competitive job placements for our people, a secretary-receptionist, and a bookkeeper. We also have about fifteen regular volunteers; we treat them like staff, except we don't pay them. There are also several groups which have continued to act as sponsors - the Kiwanis Club, the Lions Club, Mrs. Jaycees, the Minneapolis Women's Club, and several others. We consider anyone a sponsor who gives us \$100 or more per year in cash or equipment.

At the present time, all our referrals come from the Division of Vocational Rehabilitation, for all practical purposes. Occasionally a parent will pay for referral and many times we have walk-in referrals. People hear about our place and simply walk in with their son or daughter, and we don't stop them at the door and send them to DVR. We give them a tour, show them what we have to offer, and then let them go home and talk it over. If they decide our program would benefit their retardate, then they would contact the DVR counselor. In most cases, they have already been to DVR and the counselor has sent them for a tour. The general procedure

then is that the client comes in, is assigned to a staff member - usually one of the work evaluators - for some general orientation - where the time clocks are, where they eat lunch, and all the routine things the client has to know to get along in a place like ours. Then, during the first four weeks, the client is given a battery of tests by a psychologist. He is placed in a number of work stations, as many as we can manage. We like to have him in fifteen or even twenty work situations if we can. We like to have him working with a large group on the assembly line, with perhaps just two or three people on some kind of job, and on some jobs alone, to see how he reacts and responds in different kinds of situations and different kinds of jobs. At the end of the four weeks, the evaluation period is over. Sometime during the fourth week, the DVR counselor comes to meet with our staff to plan for the future - whether the individual should go into our training program, whether he doesn't need training and should go right into competitive employment, whether he should go right into our sheltered workshop as a sheltered worker, or whether he should be referred to another agency. The parents are brought in at some point and at that time we talk about sheltered workshop potential or competitive employment potential.

Now for a few specific statistics. During the past year, we served a total of 155 people and the average training period was six months. Of all the trainees who came into our program, we placed 57% in competitive employment. The other 43% we retained in our sheltered workshop or screened out of our program. I don't know how this would compare with other workshops, but I think we have been rather fortunate. We have gotten some good referrals and I think 57% placed in competitive employment is quite high. I know our average IQ has gone up a little, from about 60 up to about 64. The range is from the low 40s to the high 80s. As of today, there are 105 people enrolled in our program. The average age of this group is 25; the range is from 18 to 64, but there is only one person who is 64; if we omit her, the range is from 18 to 43. This one 64 year old we took in a couple of weeks ago; she had been in a state institution for 59 years. Let me tell you a little about her; it's interesting. She came here from Europe as a small child with her parents, and they were killed shortly after they arrived here. She couldn't speak a word of English, and got placed at Cambridge. She is legally blind, and was referred to us by Services for the Blind. She has been with us only a couple of weeks, and loves it; she is working on one of our assembly lines, packaging a Sunday School kit. She is really motivated and we hope we can keep her and find a suitable place for her in the community. It is awfully hard to keep emotionalism out of decisions; 59 years of institutional living stirs my emotionalism, anyway. Since she is legally blind, it is going to be a real challenge to find a job for her, but we are going to try. I would like to see her live a normal kind of life for what years

she has left. If our placement director can find her a job, I think I'll give him a raise!

About 99% of our work is sub-contract, and 99% of our sub-contracts are packaging and assembly. We did \$97,000 worth of this type of work last year, and paid \$43,000 in wages to the trainees and the sheltered employees. We also spent about \$20,000 in sub-sub-contracts. For instance, right now we have an abundance of work. We are sending some of this to United Cerebral Palsy. So actually, out of this \$20,000 that we sub-contracted out, a good share of it was for wages for their people so we generated more wages than the \$43,000 we paid our own people.

Training varies, as I mentioned, from no training at all after the evaluation period to extensive training periods. We try to keep this on an individual basis. For the first four weeks of the evaluation period, we get \$60 per week from DVR. Every counselor writes the authorization for four weeks of evaluation and twenty weeks of training, if we decide the client needs the training. If he doesn't need it, we cancel this out. If he needs more than twenty weeks, the counselor can increase the authorization. The twenty week figure is sort of a happy medium. During the evaluation and training periods, individuals are paid a transportation allowance only - \$3.50 a week, which just about gets them to and fro on the bus. The sheltered employees are paid on a piece rate basis whenever we can. The more they do, the more they make. You'd be surprised what an incentive this is. Some who were dragging their feet stepped up their production considerably when we put them on the piece-rate basis. Money is an incentive to most of our people. Some don't care. None of the sheltered employees make less than thirty cents an hour. We have certificates to pay some of them down to as little as ten cents, but we haven't done this yet. By certificates, I mean a permit from the Labor Department which allows us to pay a sub-minimum scale to handicapped workers. We have eighty sheltered workers right now and about 25 trainees. Of the eighty, I would guess about half could be competitively employed if we could find the right job in the right place with an employer with the right attitude. We have about six mongoloids in our place and they are pretty good workers. I hope some day we can place some of these. As you know, they have extra strikes against them because they look different, but we have found them to be steady, dependable workers. Generally our placement counselor is working to find jobs for a number of our sheltered employees. Right now we have about twenty-three people working as a result of his activities over the last eighteen months. They are making from \$1.00 to \$2.00 an hour. We have a working agreement with a nursing home in Edina whereby they will take in people for on-the-job training, as tray setters, room cleaners, bed makers, and helping with older patients to bathe and dress them and so on. We pay the nursing home \$20 a

week for training our people. If they have a position at the end of the training period, which is about a month, they will hire the individual if they think they can use him. If not, they will give him a good recommendation - or a bad one, whichever the case may be - for another nursing home. They pay the individual \$1.00 an hour while they are training him, so we reimburse them for half of the individual's salary. We hope to get more of this type of agreement. We are working on one with the World Wide Store whereby they would take in perhaps a couple of our people at a time to train them in building maintenance - janitorial types of duties. I am sold on this type of thing. It has a double benefit. It gives our people a chance to get out from under our wing, because no matter how hard we try, we are sheltered to a certain extent, and they need to get out and meet the cold facts of work, away from Opportunity Workshop. The other benefit, if we had eight or ten of these places, would be that it would generate education and interest in the community and show that these people can do a lot of things people think they can't do. It could be a community education project as well as on-the-job training.

I know we are going to run into snags with these things. There will be some youngsters who will foul something up or knock over a shelf of supplies or break something; we expect these problems and we deal with them when they happen.

I'd like to tell you a few examples of success and failure stories. When I was in the workshop in Fergus Falls we had a boy who looked pretty good. His IQ was in the low 80s, and he had some personality problems, but he was a good worker. We couldn't find anything for him to do up there. He wanted to be a baker and we tried all over town to find a bakery that would let him work for nothing; we would have paid him from the workshop. I had no success with this. Later, after I came down here, this same boy came down to University Hospital for some treatment of a skin condition, and came to our workshop. We placed him at World Wide Holiday Store. He started out at \$1.75 an hour, and just recently was raised to \$2.00 an hour. He now has about \$300 or \$400 in his savings account. He is working on his driver's license. He wants to be a licensed driver and buy a car some day. I told him not to go to a used car dealer unless somebody was with him who knew about cars, because I can just see somebody taking advantage of him and selling him a lemon. This is part of the follow-up service we offer. We help him go buy a car or start a savings account.

Let me tell you about one of our less successful individuals. He also works at this same place and we encouraged him to start a checking account. We encourage most of our people when they get jobs to start a checking account or a savings account, or both. This boy started a checking account but he forgot that when you run out of money you don't keep writing checks. He had a little problem; he wrote three twenty-dollar checks that he couldn't

cover. We had to bail him out. I think he has caught on now that when his checking account gets down to a certain point he either has to put more in or stop writing checks. This same boy got kicked out of one boarding home because of his drinking. We thought we had his alcohol problem pretty well conquered; I think it is now.

About half our people last year were from out of town. We have four boarding homes we are using now, two for boys and two for girls, through an arrangement with Hennepin County. They get their board, room and laundry for from \$75 to \$85 a month, which is a real bargain. In most cases, this is paid either by the Welfare Board or by DVR; rarely, it is paid by parents. We don't have the amount of supervision in these homes that we would like to have. We realize that the boarding parents can't treat six or eight of these adults like children. We do encourage them, especially in the girls' dorms, to sign out - like a campus situation. If a girl is going to a movie at eight, she should be back by 10:30 or 11:00 and if she signs out, the boarding parents have some idea where she is and when to expect her back.

Transportation is another problem. We have people who are riding the bus two hours in the morning and two hours at night, and our workshop day is seven hours. This is one reason that we are encouraging the group interested in starting a sheltered workshop closer to downtown; it would make a lot of difference to our clients who come from the north end of town.

Perhaps it's time for some questions now.

Question: Why has the average IQ gone up?

Answer: This happened, I think, because we changed our program somewhat. It used to be a forty-two week training program. The DVR counselor felt many times that this investment in a client, which amounted to \$1260, was a lot of money for someone who might end up just a sheltered worker. They could send an individual to the university for quite a while for \$1260, and they operate on closures. So we tried to individualize our plan and not have the training period run as long as forty-two weeks if it wasn't needed for the individual. This resulted in DVR sending us some other kinds of people - some who are emotionally disturbed, some who are mildly retarded - and this is why the average IQ is a little higher.

Question: Can you serve all the people who apply, or do you have to turn a lot of them away?

Answer: Everyone asks if we have a waiting list. No, not a formal, written-down list. We know who is coming for the next six months. We have approximately two a week. Our waiting list exists in the counselors' case loads out in the state of Minnesota. A counselor from St. Cloud may come in and say, "I've got three or four

fellows I am going to send down in the next three months or so, but the parents aren't quite ready yet." We are the third highest agency in Minnesota for referrals from DVR. Minneapolis Rehabilitation Center is first, Mankato Rehabilitation Center is second, and Opportunity Workshop is third. DVR referred eighty-eight people to us in 1964.

Question: Are you the only sheltered workshop in this area?

Answer: We are the only one that has said we deal with the retarded only. It started out to be for the retarded only, but now we are getting in some more complicated problems, people with perhaps mild retardation but an overlay of emotional problems, people who have epilepsy or cerebral palsy and some with physical handicaps.

Question: How do you do your psychological evaluations when your psychologist job is vacant?

Answer: We use a psychologist on a "moonlighting" basis. He comes over in the late afternoons and we hold a client for an hour or more, and he does the evaluation in perhaps two or three sessions. This isn't as desirable as having a full time psychologist. Of course, if we had a full time psychologist, he would do more than just tests. He would have a case load and carry other kinds of responsibilities too.

Question: After the evaluation, what specific kind of training programs do you have?

Answer: We have only two areas that are specific vocational skills: Cafeteria and building-maintenance kinds of jobs. The cafeteria training has been discontinued until we get our new addition built, but then we will pick it up again. I'm not too interested in trying to train for specific vocational skills. We are more concerned with the work adjustment type of skills. Our classes are all aimed at social and personal adjustment problems and, of course, job responsibility. If you can get a retardate - or anybody - to the point where his attitude on the job is good, he comes to work on time, he gets along with his co-workers, and with his supervisor, there is no reason why he can't do the type of job he is going to get without any specialized prior training. I like the short term on-the-job placements. They give the clients a little more experience and broader insight into the world of work. We have a practical class in money and change-making; a couple of our volunteers work on this. We have personal grooming for the boys and also for the girls; this is the only class that is not co-educational, for obvious reasons. We used our shower for the first time the other day. We thought probably the showers wouldn't get too much use; we had planned to use them as a lever, telling a client, for example, that if he didn't take a shower or bath that night he

would get one at work the next day. One of our volunteers got really fed up with one of the clients who really needed a bath and took her into the shower and I guess showed her how. This girl liked it so well she didn't want to come out!

Question: Would you talk a little about some of the general problems that sheltered employment places have?

Answer: Of course the biggest problem is that the 43% you don't place in competitive employment eventually will plug your sheltered workshop. You have to reserve so many spots for training, and if there isn't any turnover among the sheltered workers, you don't have any spots for the new sheltered workers that come along. Another thing is the problem of incentive. Some of the sheltered workers do care about money, but some of the less capable ones really don't, and the only reason they want to be there is for the companionship. This is the only incentive you can use with some of them.

Let me tell you a little more about our support. 50% comes from sub-contracts, 30% from DVR tuition, 15% from United Funds, and 5% from donations and miscellaneous sources. I've been working on the budget, trying to divide things into two parts - evaluation and training. At the rate we are being paid, the tuition is paying for the evaluation and training parts of the program. Our overhead stays about the same, but it makes some difference whether our workers are 80 sheltered workers. Suppose we had 40 normal individuals; they would do as much work and you wouldn't need as much supervision. You hear educators talk about the per pupil cost. Well, our sheltered employee deficit cost last year was \$321 per person. For comparison, consider the approximately \$1400 a year that it costs to keep an individual in a state institution, or the special education per pupil cost of about \$1,000 a year which one school administrator quoted to me. By comparison, I don't think we are doing too badly with our deficit in our sheltered workshop. If a sheltered workshop were self-supporting I would be very suspicious; I would think something was wrong and I would wonder who was being exploited if a sheltered workshop for the retarded did not have a deficit.

Question: What kind of person would you drop from your sheltered workshop group?

Answer: First, we should mention the criteria for entrance. The client has to be able to travel independently and take care of all his personal needs. We have had some who could not travel independently who were brought by their parents, but they had other assets that offset this. We have a boy now who wouldn't be able to stay if his brother weren't with him; his brother does practically everything for him. He is just too low in ability, and we won't even be able to make a sheltered worker out of him. If we don't feel that a person can become even a minimal type of sheltered worker, we generally think

he should be institutionalized and we recommend this in some cases. Everybody can't be out of an institution. Some people will advocate that we don't need institutions any longer, but to me this is ridiculous. We have a group now of about eleven who are pretty marginal in competence even for sheltered workers, and we use them as our yardsticks. If a person doesn't measure up at least to their level, we feel that he doesn't belong in the workshop. We are considering possibilities for some kind of day activity center to be attached to our workshop for some of these people. There is nothing black or white in this field; you always have the gray zone to contend with.

Question: Where do you start looking for contracts when you are establishing a new workshop?

Answer: Well, in Fergus Falls, a city of ten or twelve thousand people, I started going up and down the street. I talked to the Lions Club and the Rotary Club and the Kiwanis Club and begged for contracts and finally we started making unfinished furniture and then other things began to develop. I had never had any experience in industry. Our contract man now is from industry so he knows how things are done. Another thing I did in the early days was to go into a place and, if they would let me snoop around, I would look for nuisance jobs. Maybe they had some jobs that came up once a week and required pulling someone off his regular job to take care of. This worked, and sometimes we got some nuisance jobs. The main thing is, if you get a job, do a good job with it even if the staff has to pitch in, then you get repeat business.

We aren't going to make all of our retarded workers totally independent - there does have to be some subsidy. Let's just run a person through life, for an example. Let's say he is 20 years old, and has been through our training program. We were able to train him to a point where he earned one thousand dollars a year. If he earns a thousand dollars a year and lives to be seventy, that's \$50,000 he will earn. This isn't enough for him to live on, so we will have to set up a plan to subsidize him another \$2,000. If you take one hundred people and add up the money that you save by subsidizing them only \$2,000 a year instead of the full \$3,000 a year, it adds up to a sizable saving. I think that the three hundred and something dollars that it costs the community to underwrite our deficit is a pretty good investment.

When we look at reasons for job failure, a main reason is lack of speed and lack of ability to transfer from one job to another without a lot of supervision.

COMMUNITY ORGANIZATION AS A PROCESS

T.O. Olson

Consultant

Health and Welfare Council of Hennepin County

I work for the Health and Welfare Council of Hennepin County and my specific job is to serve as a Consultant to our Family and Child Welfare Committee. Up until 3:00 p.m. today I had been engaged in a luncheon meeting of our Board of Directors and following that had a brief interview with a reporter from one of the local papers. I tell you this for a specific purpose. Today our Board passed a resolution which will be transmitted to the House Appropriation Committee and the Senate Finance Committee of the State Legislature asking them to consider favorably the requests of the State Department of Public Welfare for staff positions for the institutions serving the mentally retarded. This action does have something to do with the process of community organization. There is a history behind this resolution. This history includes the work and efforts of a large number of individuals, organizations and groups who have worked for a very long time trying to promote better service and care for our mentally retarded patients. It's only been in recent years that we've had any significant interest in mental retardation beyond that of a few concerned individuals. Today in this state and in a good many other states this interest goes beyond these individuals, the parents' groups and the official state agencies. We have now what you might call general public awareness that there is a problem here with the level of care that we are giving to the mentally retarded. Therefore, the action taken today is made possible because all kinds of individuals like Dr. Harriet Blodgett, and all kinds of organizations like the Minnesota Association for Retarded Children, have been working patiently and fruitfully for many years. All of these small individual and group efforts have paid off in the sense that we have an awareness today so that we are hopeful that our legislature will make it possible to make a significant difference in the level of care that we are giving our retarded patients.

This is one very small and yet very current example of the process of community organization. Let us stop for a minute and examine what we mean by the term "community organization." First of all, let me ask the question, "What is meant by use of the term 'community'?" A community can vary in size from a handful of people on up to what we might call the world community. An organization may consist of parents who are interested in school children and organize themselves into a PTA. It may range in size all the way up to the individual nations that belong to the United Nations. Both types of groups are interested and in some degree engaged in the practice of what we might loosely define as community organization. If we knew enough about people and enough about the process of community organization, we might perhaps

do a better job in our world community in such places as Viet Nam or we might do a better job in terms of our relationships with Russia and China. If we had enough skill and if we had enough knowledge about how people think and how people feel, we probably could build a safer and a more productive world. In a general way I'm using the term community organization to mean the process and all of the action that is taken in trying to affect some kind of a change with the problem situation. If you believe in community organization, you must believe that people and problems can change. If you accept this concept then you must reject the philosophy of determinism. This is the idea that says that we can do nothing about the world that surrounds us. In order to practice community organization you must also reject the laissez faire philosophy which suggests that we should just sit back and let the world move along in front of us without making any effort to change it. In accepting the theory of community organization we are saying that it is possible then to do something about the social and human problems which confront us.

To put it another way, community organization is the combined efforts made by people in groups to improve their community life. We are, therefore, talking about a democratic process where numbers of people work together, think together, plan together and act together.

The individuals in the group must first of all have some formal recognition that there is a problem and that there may be ways of resolving this problem by working together. Obviously, there also has to be a group interested and willing to tackle this assignment. Selecting the appropriate group is important. Early in the process it's going to be recognized that the group is going to have to have specific information and facts concerning the problem and the alternative solutions. We may decide that it will be necessary to go out and collect some data. If we do this, we are also going to have to sort it out and evaluate it. Sometimes our information requires publicity in order to tell the story to a larger group of the public. This latter action is the implementation part of the community organization process.

A variety of kinds of groups and organizations are engaged in using the process of community organization. One example is our own Health and Welfare Council. In a specialized kind of a sense, political parties use the same process when they are trying to win support for their candidates or for their platforms. A PTA may also use the process of community organization if they are trying to gather support for a bond issue to improve the educational system.

Sometimes successful implementation requires the expenditure of funds. This makes your goal more difficult to achieve. For any significant action on the part of a large community there must be a climate of readiness. Our citizens and our legislature here in Minnesota have what I hope is a climate of readiness for action which is going to involve expenditures of additional money for the mentally retarded.

Let's take a look at some other examples. There is a lot of interest in the problems of senior citizens here in Minnesota and in many other states also. At this time there are two dozen bills in the Minnesota Legislature all having to do with providing tax relief for older people. Again, we have an example of a climate of readiness on the part of the people and government. However, much work and effort has proceeded this climate of readiness concerning senior citizens today. The Townsend Plan of the 1930's appealed a great deal to many people in this country and in its way helped to pave the road for some of the achievements we've had in recent years. In recent times we've seen a number of states provide free fishing licenses for persons over 65. In some communities you can get free checking accounts and theater tickets at half price and also cut-rate fares on the buses if you're a senior citizen. Public housing at low rents for the aged is another recent innovation. None of these things occur just by happenstance. Things that happen today are permitted to happen because of a long history that precedes the action. These would include expressions of concern about inadequate housing, inadequate financing and special needs and so what we find is a very gradual acceptance for improvement of some of these conditions. In the history of the movement for improvements for senior citizens, we find that all kinds of groups have studied the problem, have talked about it, have gathered facts and, yes, they have also written letters, made telephone calls, signed petitions and used a variety of other techniques including publicity in order to achieve the gains that we're talking about today. This is in effect, the community organization process.

Single person campaigns for major social changes cannot possibly be as effective as the collective action of informed groups. In the history of the development of our country, some of you will remember Horace Mann in his fight for free public education. Or you may recall Grace Abbott in her one woman war to abolish child labor from the American scene. Some of you will recall having read the sad stories about dependent and neglected children in the United States 100 years ago. Groups of these children were moved from the East Coast by trains to the Middle West and literally given away to anyone who was willing to take them. Labor was, of course, an important commodity and all kinds of businessmen and farmers were interested in cheap or free child labor. Grace Abbott was one of the people who was shocked by this kind of treatment of children and who worked so hard for child welfare legislation. We also had other examples in people like Dorothea Dix and Clifford Beers who were individuals carrying on one person crusades to improve the lot of the mentally ill. Some of you will recall in your reading the use of the term "alms house" which was a community facility usually stuck out in the country where they put all of society's rejects including the mentally ill, the mentally retarded, the crippled, the old, and the young and every other person who was not able to take care of himself. All of these social rejects lived in these alms houses free and were given food and shelter and were in the Biblical sense living off the alms of the church and the community. I am not intending here to ridicule or criticize people like Grace Abbott,

Dorothea Dix and Clifford Beers. These were certainly important people in the development of services in our country and we need more like them today. What I am saying, however, is that groups who work together can accomplish their goals much more quickly than is possible under what I have called the one person crusade. Our society today is a complex one and the person who stands alone isn't seen or heard by very many others. Some of our modern day crusades, of course, have been initiated by a single person who gradually got others involved.

As we think today about the process of community organization, we also should give at least some consideration to the qualifications of staff persons who might do this work on a full time basis. Instead of talking about professional education and training, I would prefer to talk about skills and ability that are important in this type of work. If we are talking about staff qualifications in the health and welfare field, we would say that first of all we would hope that the staff person would have some knowledge about the field, or fields, in which he is engaged. He may not have concentrated professional knowledge about each field that he works in, but he should have some understanding and, of course, the ability to learn quickly. The staff person also needs the ability to be able to select individuals to work in the groups who are going to be studying problems. In addition, he should also know something about the methodology that is going to be used and he should have some understanding of research techniques including the ability to gather, evaluate and interpret facts. Some skills in public relations also become important and certainly some knowledge of standards as they apply to particular programs. Thus if we were talking about congregate care, it would be important for the staff person to know something about acceptable standards and the standard setting bodies. In addition, we would hope that our staff person would have some knowledge of individual and group behavior. He should have some ability and skill to stimulate group thinking and group action.

(For the next half hour or so, the group discussed various examples of the community organization process. Some of the things discussed included such subjects as action taken by the Nicollet-Loring Park group in Minneapolis, the recent concern concerning juvenile glue sniffing, conservation programs, the AFDC program, etc.)

At this point I'd like to call your attention to what I call the problem of automation. Today it has become important to have a high school diploma to get almost any job. If this is true today, what is it going to be like 10 years from now? Currently we lose 40,000 jobs per week directly due to automation. Some of these are replaced by automation but the net loss each week totals 25,000 jobs. Our situation is further complicated because the unskilled job of today is far more technical than it was a few years ago. The janitor's job today is more complicated than it was and he is now required to know how to work a variety of kinds of pieces of machinery and in addition he must be able to have some understanding of the differences in the sweeping, cleaning and waxing compounds. What is the implication in this for the

mentally retarded? To begin with you must start with a premise that he is a handicapped person intellectually and is not as capable of learning. Consequently, he has a difficult time today obtaining and hanging on to a job. His problem is going to be much greater ten years from now. The automation experts say that currently we are using less than 1% of our potential in this field. This, therefore, poses a great challenge for us today and in the future. We are fortunate today to have high rates of employment and a good degree of economic security. It is in this kind of a climate that we have a greater opportunity to make gains for the mentally retarded. It is also very difficult to keep a high degree of interest in a particular problem for a concentrated period of time. This suggests that the public attention that we have today for mental retardation may drop off and along with that we may lose some of the gains that we have made and will be making in the near future. I personally do not have the answer for this kind of a problem but I do feel it is important to be aware of it and to begin come thinking about it.

At this point I'd like to talk with you a little bit about the importance of communications. I would suggest that communications are important in all phases of human living. Good communications are important for healthy families, businesses and all kinds of groups and organizations. A variety of techniques are used by formal organizations and businesses in trying to improve communications. Some of these techniques would include staff meetings, memorandums, newsletters, orientation programs for new personnel, and written personnel policy manuals. Along with these kinds of formal techniques of communications, we also see some interesting varieties of informal techniques. One of the most important that you have all heard about is what we would call the "grape vine." Sometimes, unfortunately, the grape vine is the only method of communication. The so-called grape vine is an important auxiliary to more formal channels of communication. The larger the organization the more difficult good communication is and the more important the formal techniques become. If the lines of communication are very long, we find greater opportunity for a breakdown in communications.

One of the basic problems in communication relates to the difference in people who are hearing or reading a message. All of us are different and we tend to put our own individual stamp on what we do hear or read and interpret it according to our own experiences and biases.

Communications are important among organizations and agencies serving the mentally retarded. Since each of you works in or will work for some kind of an organization serving the mentally retarded, it is important that you understand precisely what the function of your organization is and what the work is of comparable organizations. This is important so that we do not have unnecessary duplication of effort in our services for the retarded. How can we make appropriate referrals to other agencies serving the retarded unless we understand the services that they offer? The important point here is that good

communications and inter-agency communications lead to a better use of services and a better overall program. In other words, good communications' is a little bit like good health in that it's something that we must work on continuously.